

MOTHERS OF CHILDREN WITH CHRONIC ILLNESSES:  
A CAREGIVER BURDEN MODEL AND SUMMER CAMP AS RESPITE CARE

By

LISA JOAN MELTZER

A DISSERTATION PRESENTED TO THE GRADUATE SCHOOL  
OF THE UNIVERSITY OF FLORIDA IN PARTIAL FULFILLMENT  
OF THE REQUIREMENTS FOR THE DEGREE OF  
DOCTOR OF PHILOSOPHY

UNIVERSITY OF FLORIDA

2002

In memory of Carrie Taylor.

## ACKNOWLEDGMENTS

Many people were involved with helping me make this project happen. I would like to express my sincere gratitude to my chairperson and mentor, Dr. Suzanne Bennett Johnson, whose patience and guidance allowed my dream of studying the benefits of summer camp to become a reality. I would like to acknowledge my committee, Drs. Stephen Boggs, Gary Geffken, Kathleen Long, and Alexandra Quittner, for their input and comments at several stages in this process. This project could not have been completed without the generous funding from the Children's Miracle Network, the Geoffrey Clark Ryan Memorial Award in Pediatric Psychology, and the American Psychological Association. I would like to express my appreciation to the Boggy Creek Gang Camp for allowing me to interview the mothers of their campers. I would like to offer a special thank you to June Matthews, who helped me convince the gang that this study should happen. I would like to acknowledge my dedicated research assistants, Amy Baughcum and Nicole Karapanagiotis, for their tireless effort to reach the mothers by telephone. I am grateful that my family is always there to provide support and encouragement. Finally, I would like to thank Joyce Meltzer for unconditional love and support that has allowed me to set my goals high, and then go after them.

## TABLE OF CONTENTS

	<u>page</u>
ACKNOWLEDGMENTS .....	iii
LIST OF TABLES .....	vii
LIST OF FIGURES .....	ix
ABSTRACT .....	x
INTRODUCTION AND REVIEW OF THE LITERATURE.....	1
Impact of the Child's Illness on the Family .....	2
Concepts and Models of Caregiver Burden .....	4
Parenting Stress .....	7
Therapeutic Interventions .....	8
Support Groups .....	9
Respite Care .....	9
Therapeutic Summer Camps.....	11
Summary .....	12
HYPOTHESES .....	15
Cross-Sectional Hypotheses (Pre-Camp).....	15
Longitudinal Hypotheses .....	17
Additional Hypotheses .....	19
METHODS .....	21
Participants.....	21
Recruitment.....	24
Attrition and Missing Data.....	25
Structured Telephone Interviews .....	26
Structured Interview and Questionnaires .....	28
Demographics .....	28
Objective Stress .....	28
Subjective Stress .....	30

Outcomes .....	30
Overload .....	30
Depression-Anxiety .....	31
Maternal Distress .....	31
Recreational Activities .....	31
Time Demands .....	32
RESULTS .....	36
Preliminary Analyses .....	36
Objective Stress Calculations and Related Descriptive Statistics .....	36
Subjective Stress Calculation and Related Descriptive Statistics .....	38
Calculation of Outcome Variables and Related Descriptive Statistics .....	39
Overload .....	39
Depression-Anxiety .....	40
Maternal Distress .....	40
Recreational Activities Checklist (RAC) .....	41
Time Demands .....	41
Cross-Sectional Analyses (Pre-Camp) .....	42
Longitudinal Analyses .....	49
Longitudinal Analyses by Illness Group .....	53
Cancer on Treatment .....	54
Epilepsy .....	55
Kidney .....	56
Asthma .....	56
Cancer Not on Treatment .....	57
Additional Analyses .....	58
Cancer on Treatment .....	83
Epilepsy .....	83
Kidney .....	83
Asthma .....	83
Cancer Not on Treatment .....	84
DISCUSSION .....	97
Demographic Differences Between Illness Groups .....	97
Differences Between Illness Groups for Caregiver Burden Variables .....	99
Comparison of Outcome Variables to Normative Populations .....	101
Caregiver Burden Model .....	104
Camp Generated Respite Care .....	113
Camp Generated Respite for Each Illness Group .....	118
Study Strengths .....	124
Study Limitations .....	125
Implications and Future Directions .....	128

APPENDIX A STRUCTURED INTERVIEW OUTLINE .....	134
APPENDIX B OVERLOAD, DEPRESSION-ANXIETY, MATERNAL DISTRESS .....	140
APPENDIX C EXCESS TIME DEMANDS SCALE .....	142
APPENDIX D RECREATIONAL ACTIVITIES CHECKLIST .....	143
REFERENCES .....	145
BIOGRAPHICAL SKETCH .....	152

## LIST OF TABLES

<u>Table</u>	<u>Page</u>
1. Demographic Characteristics of the Study Sample .....	33
2. Means, Standard Deviations, and Significant Group Differences for Illness Groups and Demographic Variables.....	34
3. Mean and Standard Deviations for Attrition and Missing Data .....	35
4. Means, Standard Deviations, and Significant Illness Group Differences for Objective and Subjective Stress at Pre-Camp Assessment .....	59
5. Percent Of Caregiving Activities Rated As Stressful .....	60
6. Means and Standard Deviations for Illness Groups and Outcome Variables At Pre- Camp Assessment .....	61
7. Hierarchical Multiple Regression Steps: Predictors of Caregiving Frequency .....	63
8. Hierarchical Multiple Regression Steps: Predictors of Caregiving Duration.....	65
9. Hierarchical Multiple Regression Steps: Predictors of Subjective Stress .....	67
10. Hierarchical Multiple Regression Steps: Predictors of Overload .....	69
11. Hierarchical Multiple Regression Steps: Predictors of Depression-Anxiety.....	71
12. Hierarchical Multiple Regression Steps: Predictors of Maternal Distress.....	73
13. Hierarchical Multiple Regression Steps: Predictors of Recreational Activities .....	75
14. ANOVA Summary Tables.....	77
15: Adjusted Means and Standard Deviations for ANOVAs .....	79
17. Comparison of Means for Depression-Anxiety Using Paired t-tests.....	82
18. MANOVA Summary Tables .....	83

19. Means and Standard Deviations for MANOVAs .....	85
---	----



## LIST OF FIGURES

<u>Figure</u>	<u>Page</u>
1. Proposed model of caregiver burden for parents of children with chronic illnesses. ....	14
2. Average rating of overload for previous week .....	87
3. Average rating of depression-anxiety for previous week .....	88
4. Average rating of maternal distress for previous week .....	89
5. Average time spent in recreational activities during the previous week .....	90
6. Comparison of Objective Stress, Subjective Stress, and Outcomes for Cancer on Treatment .....	91
7. Comparison of Objective Stress, Subjective Stress, and Outcomes for Epilepsy.....	92
8. Comparison of Objective Stress, Subjective Stress, and Outcomes for Kidney.....	93
9. Comparison of Objective Stress, Subjective Stress, and Outcomes for Asthma.....	94
10. Comparison of Objective Stress, Subjective Stress, and Outcomes for Cancer Not on Treatment .....	95
11. Average rating of time demands for previous month .....	96

Abstract of Dissertation Presented to the Graduate School  
of the University of Florida in Partial Fulfillment of the  
Requirements for the Degree of Doctor of Philosophy

MOTHERS OF CHILDREN WITH CHRONIC ILLNESSES:  
A CAREGIVER BURDEN MODEL AND SUMMER CAMP AS RESPITE CARE

By

Lisa Joan Meltzer

August 2002

Chairman: Suzanne Bennett Johnson, Ph.D.  
Major Department: Clinical and Health Psychology

This study empirically supported a theoretical model of caregiver burden for mothers of children with chronic illnesses. In addition, this study investigated whether summer camps for children with chronic illnesses provided respite care for mothers. Participants were 179 mothers whose children with cancer, epilepsy, kidney disorders and asthma attended a summer camp for children with chronic illnesses. Mothers were interviewed one month before their child attended camp, while their child was at camp, and one week and one month after their child returned home from camp. Mothers completed a structured interview that assessed objective stress (caregiving frequency and caregiving duration), subjective stress (stress related to caregiving), and psychosocial outcomes (overload, depression-anxiety, maternal distress and recreational activity time). Multiple regression analyses were used to examine predictors of caregiver burden, while

repeated measures ANOVAs were conducted to examine the impact of respite care on caregiver burden over time.

This study supported the proposed model of caregiver burden, demonstrating an indirect effect of caregiving activities on psychosocial outcome variables through subjective stress. Significant predictors of caregiving frequency and duration included child's illness and child's sex, with mothers of all illness groups reporting more objective stress than mothers of children with cancer on treatment, and mothers of boys reporting more objective stress than mothers of girls. Caregiving frequency, caregiving duration, and illness group significantly predicted subjective stress, with mothers who reported greater objective stress, or who had children with cancer on treatment or asthma reporting greater caregiving stress. All psychosocial outcome variables were predicted by caregiving stress. Additional predictors included percent of time mother was the primary caregiver, maternal employment status, and maternal race. The results from this study also indicated that summer camps for children with chronic illnesses provided respite care for mothers by improving psychosocial outcomes during the respite care (camp), with some benefits maintained for up to one month after camp ended. Results from this study highlight the importance of studying stress related to disease specific caregiving, and the relationship between caregiving stress and outcomes. In addition, conceptualizing summer camps as respite care allows these camps to serve as an intervention for caregiver burden.

## INTRODUCTION AND REVIEW OF THE LITERATURE

Due to advances in medical technology, many illnesses that were once fatal for children are now considered chronic physical conditions. Consequently, current pediatric psychology research primarily focuses on adjusting to and coping with a chronic illness, compliance with medical regimens, and quality of life issues for the patient and family. These areas are important to study, as findings from the research can be applied clinically to improve psychosocial and medical outcomes. A "chronic physical condition" is defined as a physical, usually non-fatal condition that (1) interferes with daily functioning for more than three months in a year; or (2) causes hospitalization lasting more than one month a year; or (3) is thought at the time of diagnosis to result in either of the preceding (Pless & Pinkerton, 1975). Most chronic physical conditions can be medically managed, although most cannot be cured (Wallander & Thompson, 1995). Approximately 10-20% of the general child population have chronic illnesses however only about 20-25% of these children are considered to have more severe conditions, with greater functional impairment (Newacheck, Budetti, & Halfon, 1986). The most common serious chronic conditions are asthma, seizure disorders, diabetes, cerebral palsy, and arthritis (Gortmaker & Sappenfield, 1984). It has been estimated that more than one million children have a serious chronic illness or disability that requires ongoing and comprehensive medical care (Quittner & DiGirolamo, 1998).

Although chronic physical conditions may have a significant impact on the child, the impact of these illnesses on the family must also be considered. Kazak et al. (1995)

cited multiple reasons why it is important to include the family when studying the impact of chronic physical conditions. Children rarely come unaccompanied to a clinic or hospital for medical care, and usually are unable to give consent for treatment. A child's understanding of having an illness and its long term implications is limited by developmental stage, requiring the parent to become knowledgeable about medical treatments, which can often be complex and long-term. In addition, as a parent's understanding of the illness and its long-term consequences increase, the parent may experience more emotional distress than the child. With advances in medical technology, medical care is also being moved more frequently into the home, requiring parents to administer complex daily medical regimens. These responsibilities can take a toll on parents, requiring not only time, but also physical and emotional energy, often resulting in significant parental stress.

The following review will begin with a brief discussion of how caring for a child with a chronic illness can disrupt the family. This will be followed by an examination of the concepts and theoretical models related to caregiver burden and their application in pediatric psychology research. Finally, a review of the existing literature on therapeutic interventions for parents of children with chronic physical conditions will demonstrate the need for further empirical research on the effectiveness of interventions that reduce caregiver burden.

### Impact of the Child's Illness on the Family

The literature has consistently found that parenting a chronically ill child significantly affects the family in multiple ways. For parents, caring for a child with a chronic illness is a great stress, combining the demands of parenting with the emotional

and physical burdens of caring for the child's chronic illness (Drotar, 1992). Parents of chronically ill children have reported more anxiety and depression than parents of healthy children or normative populations. This has been found in studies of parents of children with renal failure (Fielding et al., 1985), cystic fibrosis (CF) (Breslau, Staruch, & Mortimer, 1982; Mullins et al., 1991; Quittner, DiGirolamo, Michel, & Eigen, 1992; Thompson, Gustafson, Hamlett, & Spock, 1992), recurrent abdominal pain (Hodges, Kline, Barbero, & Flanery, 1985), and physical disabilities (Gordon, Daniele, & Diller, 1992). Parents have also reported higher levels of parenting stress when caring for children with craniofacial anomalies (Speltz, Armsden, & Clarren, 1990), type 1 diabetes (Wysocki, Huxtable, Linscheid, & Wayne, 1989), developmental delays (McKinney & Peterson, 1987), CF (Goldberg, Morris, Simmons, Fowler, & Levison, 1990; Quittner et al., 1992), congenital heart disease (Goldberg et al., 1990), and hearing impairments (Quittner, Gluekauf, & Jackson, 1990). Finally, parents have reported greater role restriction and more limited social functioning when caring for children who are medically fragile (Patterson, Leonard, & Titus, 1992), have spina bifida or cerebral palsy (Breslau et al., 1982; Wallander et al., 1989), or CF (Quittner, Opiari, Regoli, Jacobsen, & Eigen, 1992). Together these findings suggest that caring for a child with a chronic condition can have a serious impact on a parent's general well being and overall functioning.

However, when examined as a whole, several limitations in this literature can be identified. First, most studies lack a theoretical model or a clear definition of caregiver burden. Next, the impact of caring for a child with a chronic illness is often measured in terms of general parenting or global stress, neglecting the importance of stress directly or



indirectly related to caring for their child's illness. Finally, although the literature suggests that parental distress related to being a caregiver is prevalent, there are only a limited number of studies that have examined the benefits of interventions for caregivers. An examination of these issues in the current literature will demonstrate the need to improve previous methodology and to empirically evaluate an intervention to relieve caregiver burden.

### Concepts and Models of Caregiver Burden

Although it may appear to be only semantics, caregiver burden has not been defined in the pediatric psychology literature, implying that stress related to caregiving is simply an obligation of parenting, resulting in additional parenting stress. To understand why caregiver burden should be examined as an independent entity, one must turn to the adult literature on caregivers of patients with Alzheimer's disease (AD) for a definition and theoretical model. George and Gwyther (1986) defined caregiver burden as the physical, psychological or emotional, social, and financial problems that can result from caring for impaired older adults. However, this definition could easily be modified for parents caring for children with chronic physical conditions. In addition to the operational definition of caregiver burden, the most extensively researched theoretical model of caregiver burden has evolved in the adult literature (Pearlin, 1994; Pearlin, Mullan, Semple, & Skaff, 1990).

Pearlin's model has three primary domains: stressors, mediators, and outcomes (Pearlin, 1994). Pearlin differentiates between primary and secondary stress, with primary stress being caused directly by caregiving activities. Primary stress can be both objective (for example, the level of work the caregiver must do) and subjective (related

more to the subjective states and experiences of the caregiver). Stress that surfaces in areas of life outside of caregiving is secondary stress (for example, role strain or job conflict). Mediators are defined as those actions and resources that can influence the direction of the stress process and blunt its impact on individuals. Coping and social support are the most commonly tested mediators in stress research. Finally, there are outcomes, including psychological, physical, immunological, and social functioning. By examining these separate components of the stress process, Pearlin argues that more effective interventions can be identified (Pearlin, 1994; Pearlin, Mullan, Semple, & Skaff, 1990).

Although Pearlin's model has been the most extensively defined and empirically supported, there are two empirically based models that have been proposed in the pediatric psychology literature to explain caregiver stress and burden. It is important to examine these models, noting the similarities to Pearlin's caregiving model, and leading to the conclusion that Pearlin's model can effectively be applied to caregivers of children with chronic illnesses.

Wallander et al. (1989) developed the disability-stress-coping model. In this model, multiple risk factors (primary stressors) are identified, including a child's physical disease or disability, the strain of the demands of daily living activities, and psychosocial stress. The model states that the impact of these risk factors is moderated by resistance factors such as social-ecological factors, intrapersonal factors, and coping. Disability/disease parameters (objective stressors) are also believed to have both a direct effect on adaptation (outcomes), and an indirect effect by increasing functional care strain and psychosocial stress (subjective stress).



Although this model attempts to account for adaptation in parents of chronically ill and physical handicapped children, the model's comprehensive nature has made it difficult to study in its entirety (Thompson & Gustafson, 1996a). In addition, there has been a lack of empirical findings to support multiple parts of this theory (Wallander & Varni, 1998). However, the relationship between objective stress, subjective stress, and outcomes parallels Pearlin's model, suggesting that caregiver burden may play an important role in maternal adaptation.

The transactional stress and coping model (Thompson et al., 1992) also provides a framework for examining the role a child's chronic illness plays in maternal adjustment. In this model, chronic childhood illness is viewed as a stressor to which the family attempts to adapt (primary stressor). Three psychosocial/mediational processes (mediators) are proposed: (1) the cognitive processes of stress appraisals and efficacy expectations, (2) the utilization of palliative and/or adaptive methods of coping, and (3) social support in terms of family functioning. This model has been supported empirically (Thompson & Gustafson, 1996a) and does a good job of examining the mediational processes between the child's illness and maternal adjustment. Again, this model is similar to Pearlin's caregiving model (Pearlin defined coping and social support as the most commonly regarded mediators), suggesting the relevance of applying Pearlin's model to pediatric populations.

Based on these conceptualizations, this study proposes a modification of Pearlin's model to explain how interventions with parents of children with chronic illnesses may relieve caregiver burden. As seen in Figure 1, objective stress is defined as home medical treatments (e.g., daily medications, peak flow meter monitoring), medical

appointments or treatments outside the home (e.g., dialysis, chemotherapy), and nighttime care (requiring the mother to awaken during the night). Subjective stress is the mother's perception of stress related to each of the objective stressors. Outcomes are defined in terms of overload, depression-anxiety, maternal distress, and time spent in recreational activities.

This model suggests that the objective stress of caring for a child with a chronic illness can directly and indirectly impact outcomes. Due to the level of care involved, objective stress may directly result in psychological distress or reduced time to pursue recreational activities. On the other hand, level of care may lead to subjective stress (perceived feelings of caregiver stress), which then creates psychological distress or insufficient energy for recreational pursuits.

### Parenting Stress

Without a clear definition of caregiver burden, most researchers have examined parenting stress without acknowledging the fact that caring for a child with a chronic illness is above and beyond the role of "normal" parenting. The impact of caring for a child with a chronic physical condition is usually measured in terms of general parenting stress (e.g., Parenting Stress Index), emotional distress (e.g., Beck Depression Inventory), and to a limited degree role and social restrictions (e.g., CF Role Strain Index). Stress related to parenting is lumped together with the unique stress that may be associated with caring for a chronically ill child.

The results from two studies that have compared global vs. specific types of parenting stress demonstrated that, in fact, parents of children with chronic physical conditions experience different types of stress than parents of healthy children. Quittner,

Gluckauf, and Jackson (1990) compared life stress, generic parenting stress (using the PSI), and illness-specific stress (children with severe to profound hearing losses), reporting that the impact of the tasks related to caring for a child who is deaf was most predictive of maternal depression. As part of their mediational model, Thompson et al. (1992) compared the cognitive processes of appraising daily hassles and illness tasks (caring for a child with CF). They found that there was only 25% shared variance in reports of daily hassles and illness specific stress. Together, the findings from these studies suggest that the stress related to being a parent and being a caregiver of a chronically ill child might not be the same, requiring different approaches in terms of measurement and intervention.

#### Therapeutic Interventions

In the pediatric psychology literature, family focused interventions are sparse (Wallander & Varni, 1998). There are several possible explanations for the lack of these interventions in the literature. First, the field of pediatric psychology as a whole is still young in terms of the research and development of intervention programs. Although most pediatric psychologists recognize the importance of the family in terms of the child's coping and adjustment, interventions have primarily targeted reducing the stress, anxiety, and depression of the affected child. Although parents of chronically ill children have been identified as experiencing more depression, anxiety, and stress than parents of children without chronic physical conditions, the lack of recognition of these outcomes as "caregiver burden" may have limited the number of therapeutic interventions aimed specifically at parents. Finally, of the existing interventions, many are described

anecdotally, suggesting that some interventions do exist, but their effectiveness remains to be studied empirically.

### Support Groups

One intervention for parents of children with chronic physical conditions that has been reported in the literature involves social support, either through mentors or support groups. There are anecdotal descriptions of support groups for parents of children with fatal genetic illnesses (Mack & Berman, 1988) and CF (Matloff & Zimmerman, 1996). Positive outcomes identified in these groups include parents collaborating on a common goal (i.e., providing information to pediatricians about the common symptoms of CF) and reducing social isolation. A non-randomized empirical study of a support group for parents of children on a neonatal intensive care unit (Roman et al., 1995) reported that parent-to-parent support significantly reduced anxiety and tension and increased self-esteem four months post-discharge. The interaction between veteran NICU parents and new NICU parents provided emotional, social, and educational support to the new parents. Ireys and colleagues (1996) found that social support in the form of mentors resulted in reported improvements in adjustment and social support for mothers of children with juvenile rheumatoid arthritis. These studies describe how social support interventions can be beneficial for parents of children with chronic physical conditions. Although this type of support may function as a mediator by reducing parental stress, social support interventions do not alleviate the primary stress related to caregiver burden.

### Respite Care

Respite care is one type of intervention that can reduce both objective and subjective stress related to caring for a child with a chronic illness. Respite care is

defined as short-term, temporary care for disabled or chronically ill people living at home (Joyce, Singer, & Isralowitz, 1983). The service can be provided in the home or in a residential facility (Marc & MacDonald, 1988). The purpose of respite care is to give parents and families a break from the physical and emotional demands of caregiving (Joyce et al., 1983). It is possible that respite care could have a direct and indirect effect on outcomes. Direct effects may result from removing the immediate and objective stress related to caring for the child (e.g., feeding, giving medications), resulting in decreased psychological distress and increased opportunities for social interactions. The indirect effect of respite care results from reduced perceptions of stress related to caregiving (subjective stress).

Although there are few studies of respite care for children with chronic illnesses, multiple studies have examined the benefits of respite care for families who have a child with developmental disabilities. In-home respite care has been found to reduce caregiver burden by relieving familial stress (Joyce et al., 1983; Marc & MacDonald, 1988; Rimmerman, 1989), improving family functioning (Halpern, 1985; Marc & MacDonald, 1988), improving parental attitudes toward their child (Halpern, 1985; Marc & MacDonald, 1988), reducing social isolation (Joyce et al., 1983), and decreasing parental depression (Herman & Marcenko, 1997). Together these findings suggest that in-home respite care is valuable and serves multiple functions for family members.

Benefits of out-of-home respite care have also been reported for mothers of children with cerebral palsy and mental retardation. In a study of the immediate and short-term effects of overnight respite, Botuck and Winsberg (1991) found that while the child was away from home, mothers reported increased feelings of well-being and

decreased depressed mood, more time resting and sleeping, more grooming and self-care, an increase in leisure activities and active social contact, and less time in child care and household duties. Three to four days after the respite ended, mothers' activity levels in terms of childcare returned to baseline, but the increases in positive affect and decreases in depression remained.

Although the findings of Botuck and Winsberg (1991) are limited by a small sample size ( $n=14$ ), the authors suggest that overnight respite can be beneficial for mothers of children with chronic conditions. In addition, this study identifies an existing form of respite care for mothers of children with chronic physical illnesses, namely overnight summer camps.

#### Therapeutic Summer Camps

Therapeutic summer camps began operating after World War II, as children with chronic illnesses were often excluded from regular summer camps. The number of camps has increased dramatically in recent years (Biggs, Heinrich, Jekel, & Cuono, 1997; Bluebond-Langner, Perkel, Goertzel, Nelson, & McGeary, 1990), including camps for children with asthma, burns, cancer, diabetes, epilepsy, and many other illnesses. These camps provide an opportunity for children to "just be kids," and interact with other children who have a similar condition. Most camps are one to two weeks and include regular camp activities such as fishing, boating, hiking, and arts and crafts.

There are few published studies documenting the benefit of therapeutic summer camps, and almost all of these have focused on children. The existing empirical studies have found that therapeutic summer camps (1) increase disease knowledge for children with diabetes (Harkavy et al., 1983) and children with cancer (Bluebond-Langner et al., 1990), (2) increase medical regimen compliance during camps for children with diabetes



(Spevack, Johnson, Riley, & Silverstein, 1989) and CF (Rubin & Geiger, 1991), and (3) improve attitudes toward illness and reduce trait anxiety for children with asthma, diabetes, and spina bifida (Briery & Rabian, 1999). The more general psychosocial benefits of camp for children have not been as conclusive, with mixed results for changes in self-esteem in children with burns (Biggs et al., 1997), self-concept in children with CF (Rubin & Geiger, 1991), and changes in locus of control in children with diabetes (Moffatt & Pless, 1983).

Only one study examined the benefits of therapeutic summer camps for the family. Smith et al. (1987) studied eighteen pediatric cancer patients and their families before, during and after a one-week summer camp experience. Mothers reported an increase in the number of activities with others outside the family from the pre-camp to the during-camp assessment. In addition, two weeks after camp, mothers' social interactions continued to increase, a finding that was maintained four weeks post-camp. It is also interesting to note that siblings of the cancer patients reported not only an increase in social activities with the family during and after camp, but a decrease in the number of activities with others outside of the family. Both findings were maintained four weeks post-camp. The results from this study suggest that camp can play an important role in relieving some of the caregiver burden mothers experience.

### Summary

An empirical investigation of caregiver burden and respite care as an intervention for parents' of children with chronic illnesses is clearly needed. Caregiver burden may result from the many demands related to caregiving, resulting in increased perceptions of stress related to caregiving, which in turn may result in parents experiencing greater

psychosocial distress. As overnight respite care removes the child from the home, caregiving requirements decrease. In turn, parents may experience decreased feelings of subjective stress, psychological stress, and have more time for recreational and social pursuits. The growing number of therapeutic summer camps for children with chronic physical conditions may provide respite care for parents, removing the child from the home for one to two weeks during the summer. The purposes of this study were to (1) document caregiver burden in mothers of children with chronic illnesses; and (2) empirically measure the effect of respite care provided by camp on maternal objective and subjective stress, as well as the impact on psychological distress and recreational activity time. Data were examined both cross-sectionally (before camp) and longitudinally (before, during, and after camp).



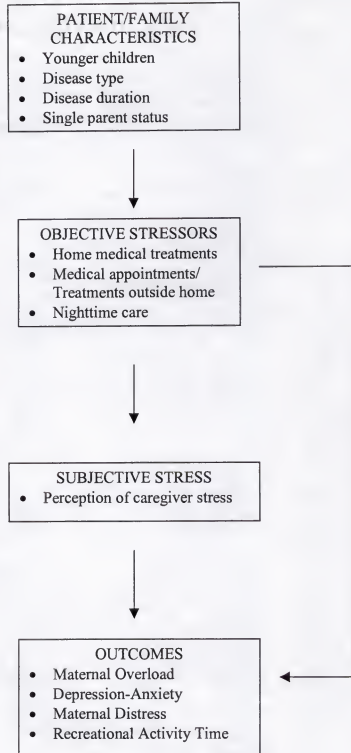


Figure 1. Proposed model of caregiver burden for parents of children with chronic illnesses.

## HYPOTHESES

### Cross-Sectional Hypotheses (Pre-Camp)

The following hypotheses were proposed in order to test the modification of Pearlin's theoretical caregiver burden model.

#### *1. Demographic variables will predict objective stress.*

Younger age, illness group, shorter disease duration, and single parent status were expected to predict greater frequency and duration of objective stress. More specifically, younger children typically require more care due to their developmental level.

Each pediatric illness has a different presentation, requiring different levels of care. For example, treatment for kidney disease can include either frequent dialysis or a transplant, both of which require a significant amount of time from the caregiver. Asthma, on the other hand, requires daily medical management, but if cared for properly, can be an illness that the child simply lives with. Thus mothers of children with illnesses that required more complex daily management were expected to report more objective stress (frequency and duration of caregiving activities) than mothers of children whose illnesses require less intense medical regimens.

Due to the many adjustments in daily functioning that must be made following the diagnosis of a chronic illness, mothers have reported increased levels of stress immediately after diagnosis (Kovacs et al., 1985; Quittner et al., 1992). This suggests

that mothers of children with a more recently diagnosed illness may report greater objective stress than mothers of children with longer duration illnesses.

Finally, due to the lack of additional caregiver support, single mothers were expected to report a greater level of objective stress than mothers who have a spouse to share some of the caregiving responsibilities.

*2. Greater objective stress will be related to greater subjective stress.*

As caregiving tasks increase in frequency or duration, an increased demand is placed on mothers. Thus it was expected that mothers who reported greater objective stress (frequency and duration of caregiving activities) would also report more subjective stress (perceived caregiving stress).

*3. Greater objective stress will predict greater negative outcomes.*

Objective stress was believed to have a direct effect on maternal outcomes, thus mothers who reported greater objective stress (frequency and duration of caregiving activities) were expected to also report greater psychological distress (overload, depression-anxiety, maternal distress) and less time spent in recreational activities.

*4. Greater subjective stress will predict greater negative outcomes.*

As caregiving can feel relentless and exhausting at times, the perception of greater caregiver stress was expected to lead to greater caregiver psychological distress (i.e., overload, depression-anxiety, maternal distress) and less recreational activity time for mothers.

*5. Subjective stress mediates the relationship between objective stress and outcomes*

The proposed model fits the definition of a mediator model: changes in the independent variable (objective stress) affect the outcome both directly and indirectly by

causing changes in the mediator (subjective stress), which then leads to changes in the outcomes (Baron & Kenny, 1986; Holmbeck, 1997). According to Baron and Kenny (1986), four conditions must be met for a variable to be considered a mediator: (1) the predictor (objective stress) must be significantly associated with the hypothesized mediator (subjective stress), (2) the predictor (objective stress) must be significantly associated with the dependent variable (outcomes), (3) the mediator (subjective stress) must be significantly associated with the dependent variable (outcomes), and (4) the impact of the predictor (objective stress) on the dependent measure (outcomes) should be reduced after controlling for the mediator (subjective stress).

#### Longitudinal Hypotheses

As mothers do not have to care for their child's illness during the camp session, it was assumed that the mother did not experience objective stress while the child was away. Therefore, it was hypothesized that camp would provide respite care for all mothers. The camp that was used in this investigation offered eight one-week sessions, with each session designated for a different illness population. Although this study had no control group of healthy children, preliminary analyses demonstrated significant differences between the caregiving stress of mothers of children with cancer on and off treatment. Thus, we decided to use the cancer not on treatment group as a comparison group. As these children are in remission from their disease, they require a minimal amount of caregiving related to their illness (e.g., maintenance medications, occasional medical appointments). Consequently, objective stress was relatively low for this group of children. In addition, the collection of data across multiple camp sessions allowed for a type of multiple baseline design. A replication of the changes in the outcome variables

before, during, and after camp for each illness group included in the study would suggest that as an intervention, camp does provide respite care for mothers.

*1. Objective stress, which is assumed to decrease while the child is at camp, will remain at baseline levels one week and one month post-camp.*

It was assumed that the objective stress related to caring for a child with a chronic illness would decrease while the child was at camp since the mother was no longer responsible for the day to day care of her child. However, camp only provides a short-term break from caregiving, with the treatment demands of the child's illness remaining the same when the child returns home. Thus, objective stress was not expected to change one week or one month after the camp session ended. Some children may have learned how to manage their illness more independently at camp, thus it was possible that the level of objective stress would decrease post-camp for some mothers.

*2. Removing the objective stress related to caring for a child with a chronic illness will reduce subjective stress after camp, with changes maintained at least one week post-camp, and up to one month post-camp.*

Although objective stress was expected to remain at baseline levels following camp, it was hypothesized that the respite care provided by camp would decrease the mothers' perception of stress related to caregiving (subjective stress). It was expected that subjective stress would be lower one week after the child returned home from camp, as mothers would still be enjoying the benefits of having a week without caregiving duties. However, the maintenance of these changes one month after camp was not predicted. As the level of objective stress was expected to remain at baseline level after camp, the day to day burden of caregiving may eventually negate the emotional benefits mothers experienced while their child was attending camp.

*3. Removing the objective stress related to caring for a child with a chronic illness will change outcomes (reduce psychological distress and increase time spent in recreational activities) during camp, with changes maintained at least one week post-camp, and up to one month post-camp.*

The respite provided by camp allows mothers a week without the daily objective stress of caring for the child with a chronic illness. The reduction of objective stress was expected to improve outcomes by reducing feelings of overload, maternal depression and anxiety, maternal distress, and increasing recreational activity time while the child is at camp. Similar to the findings of Botuck and Winsberg (1991), it was expected that mothers would continue to display improved outcomes one week after camp. However, by definition respite care only provides temporary relief. Thus, the maintenance of these findings one month post-camp was not expected. Although Botuck and Winsberg found respite care reduced maternal depression and increased positive affect, their follow-up period was only 4 days post-respite. Smith et al. (1987) found increases in social activities to be maintained 4 weeks post-camp, but they did not examine changes in maternal distress. The lack of conclusive previous findings suggests that changes in psychological distress and social activities one month post-camp could be either maintained or return to baseline levels.

#### Additional Hypotheses

*The benefits of respite care will generalize to a more stable psychological phenomenon (i.e., time demands).*

Caregiver burden can extend beyond psychological distress, impacting a mother's personal growth and development in terms of interpersonal interactions, employment, and outside interests. However, if respite care provided lower levels of psychological distress, mothers may perceive fewer demands on their time. Therefore, it was expected

that if the benefits of respite care were found (changes in psychosocial outcomes), mothers would report fewer time demands one month after camp compared to one month before camp.

## METHODS

### Participants

Participants were 179 mothers of children with cancer, epilepsy, kidney disorders, or asthma who attended the Boggy Creek Gang Camp (BCGC) in Eustis, Florida during the summer of 2000. The total sample of mothers was 72.6% Caucasian and 66.5% married; the children ranged in age from 6.5-17 years. See Table 1 for complete demographic data.

Although fathers and other caregivers (e.g., grandmothers) may also experience caregiver burden, mothers were the focus of this study because mothers are typically the primary caregiver (Hauenstein, 1990). The targeted number of subjects per session ( $n=50$ ) was chosen based on two criterion: (1) number of expected eligible campers (e.g., a maximum of 50 campers with kidney disorders had applied in previous years) and (2)  $n=50$  per group would provide sufficient power to detect medium to large effect sizes for the proposed analyses in this study (Cohen, 1992). Due to the small number of applications from kidney campers ( $n=44$ ) for summer 2000, the target number of 50 was not reached for this group.

Illness groups were selected based on amount of time required for medical care (both at home and away-from-home appointments/treatments), level of functional impairment, and severity of illness. More specifically, cancer is an acute illness that can be life threatening. When diagnosed, cancer usually creates a sudden change in family



functioning (Dahlquist, Czyzewski, Copeland, & Jones, 1993; Manne et al., 1995).

Although home medical treatments are not time consuming, medical appointments and hospitalizations can be frequent and time intensive. Although 55% of the children attending camp were not currently receiving treatment, we originally planned to have only one cancer group. This decision was based on studies by Bakarar and colleagues, demonstrating that parents continue to experience distress related to reminders of the cancer (in this case, sending the child to a "cancer camp") as well as daily stress of medical sequelae (Barakat et al., 1997; Barakat et al., 1998). However, in our sample, subjective stress significantly differed between the on and off treatment groups. Thus although 51 mothers of children with cancer were recruited to participate, they were divided into two groups, on treatment ( $n=23$ ) and not on treatment ( $n=28$ ). Due to the significantly lower levels of both objective and subjective stress reported by mothers of children with cancer not on treatment compared to all illnesses, we decided to use this group as a comparison group.

Epilepsy and other seizure disorders require constant supervision for seizure activity, as well as an often complex medication regimen. Side effects from anticonvulsant medications include impaired cognitive functioning, hyperactivity, and possible impairments of adaptive behaviors (DuPaul & Kyle, 1995). These side effects may significantly influence the level of stress caregivers experience.

Approximately 20% of the campers with kidney disorders were on some type of dialysis (either daily home dialysis or hemodialysis for four hours, three times a week), while approximately 30% of the campers were transplant recipients, requiring daily immunosuppressants and other medications. The other half of the kidney campers

required some type of daily medication management. Between one-third and one-half of the entire kidney camper population required multiple catheterizations daily to relieve their bladders (due to incomplete camper files, an exact number is not available).

Finally, children with severe asthma are required to use meter dose inhalers (MDIs) multiple times per day and are encouraged to monitor pulmonary functioning with a daily peak flow assessment, while all children with asthma must carry a rescue inhaler in case of an asthma attack. Based on physician reports, of those attending camp, approximately 40% met NIH criteria for moderate persistent to severe persistent asthma, while approximately 27% met NIH criteria for mild intermittent to mild persistent asthma. The other third of the asthma camper files were missing the NIH diagnosis.

To examine whether there were any demographic differences between disease groups, one-way ANOVAs were conducted using the pre-camp data. Between disease group differences were expected because of the camp's lower age limit for asthma campers (12 years) compared to all other illness groups (16 years). The between disease-group age difference was confirmed,  $F(4, 174) = 15.0, p < .01$ . Other significant between disease-group differences occurred for the child's duration of disease  $F(4, 174) = 19.21, p < .01$ , child's previous camp experience,  $F(4, 174) = 3.90, p < .01$ , and maternal age,  $F(4, 174) = 3.44, p = .01$ . Means, standard deviations, and significant group differences can be seen in Table 2.

Post-hoc analyses, using the Tukey Honestly Significant Difference (HSD) test, indicate that children with cancer on treatment and asthma were significantly younger than children with epilepsy, kidney disorders, and cancer not on treatment. Duration of disease for children with cancer (both on and off treatment) was significantly shorter

compared to children with epilepsy, kidney disorders, or asthma. Children with epilepsy and cancer not on treatment had attended camp for significantly more summers than children with asthma. Finally, mothers of children with cancer on treatment were significantly younger than mothers of children with epilepsy and kidney disorders.

### Recruitment

All mothers of campers from the selected four sessions received a letter in the mail approximately six weeks before their child's camp session began. This letter explained the study's purpose and procedures, and if the mother verbally agreed by telephone to participate, the letter served as the consent form. This study was approved by the University of Florida Health Science Center's Institutional Review Board. Mothers of the children attending the four selected sessions (cancer, epilepsy, kidney, and asthma) were listed alphabetically and 266 were selected using a random number table. The mothers who were selected received a phone call from the principal investigator, who again explained the purpose of the study, what participation would require, and reinforced that the mother could refuse to participate or withdraw from the study without any penalty to her child's camping experience this year or in future years. Mothers were also informed by letter and telephone that the camp would receive a donation for each call completed. A \$2000 donation to the Boggy Creek Gang Camp was made in November 2000 in honor of the mothers who participated.

Of the 266 mothers selected with the random number table, 35 were not eligible for the following reasons: phone not in service ( $n=14$ ), the mother did not speak Spanish (some interviews were conducted in Spanish) or enough English to communicate with the interviewer ( $n=8$ ), respondent was not the child's mother ( $n=6$ ), the child was not

attending camp ( $n=5$ ), one mother relied on the neighbors phone, and one mother was attending camp as a nurse.

Every mother randomly selected to participate was called at least five times, at various times of the day, during both weekdays and weekend days. When 50-55 mothers per illness group agreed to participate, recruitment calls were ceased. Thirty-six mothers were not reached during the designated recruitment period, resulting in 195 eligible participants. Of those who were eligible, 10 mothers declined to participate stating a personal lack of time ( $n=7$ ), interest ( $n=2$ ), or desire to "put the experience (of her child's illness) behind her" ( $n=1$ ). Of the mothers who declined to participate, 60% had children with cancer, significantly more than all other illness groups combined, Fisher's exact test,  $p = .03$ .

#### Attrition and Missing Data

Of the 185 mothers who agreed to participate in the study, six were dropped from all analyses (two were never reached after the recruitment call, children of the other four mothers were not at home during the relevant pre-camp baseline period, thus we were unable to collect baseline caregiving data), resulting in the final sample of 179 mothers.

T-tests and Fisher's exact tests were used to examine differences between subjects who agreed to participate and then did not complete any telephone interviews ( $n = 6$ ) and those who completed the pre-camp interview ( $n = 179$ ). 80% of those who did not participate had children with asthma versus any of the other illnesses combined, Fisher's exact test,  $p = .03$ .

Of the 179 mothers who participated in this study, 80% were reached during all four assessment times. Eighteen mothers were not included in the longitudinal analyses

for the following reasons: due to a medical exacerbation, the child did not actually attend camp ( $n = 13$ ), the child had a negative experience at camp (e.g., the child was sent home early due to behavior problems or was bullied by another camper,  $n = 3$ ), one mother stated that the study “annoyed her,” and one mother was never reached after the initial interview.

Differences between those mothers who completed only one interview versus two or more interviews were examined using t-test and chi-square analyses. Significant differences were found with those who dropped after the pre-camp interview reporting less camp experience,  $t(177) = 2.47, p < .05$ , lower income,  $t(153) = 2.11, p < .05$ , greater percentage of time as the primary caretaker,  $t(177) = -2.58, p < .05$ , lower frequency of caregiving duties,  $t(177) = 2.39, p < .05$ , and lower subjective caregiving stress,  $t(177) = 3.72, p < .01$ . Means and standard deviations are reported in Table 3. In addition, of those who dropped, 78% were minority children, Fisher’s exact test,  $p < .05$ .

#### Structured Telephone Interviews

Participants completed four structured interviews by telephone: (1) Pre-camp – three to four weeks prior to the start of the camp session, (2) During camp – during the final two full days of the camp session (the 5th and 6th day), (3) Post-camp – one to two weeks after the end of camp, and (4) Follow-up – four to five weeks after the end of camp. These interviews were conducted by a graduate student and an undergraduate student, both of whom received extensive training related to the study’s purpose, how to respond to different responses given by mothers, and disease specific information that would ensure their ability to ask appropriate questions. In addition, all telephone calls were tape recorded (with the permission of the mothers) for quality assurance purposes.

Tapes were randomly selected for review, allowing for feedback and additional training to be provided for the interviewers.

The telephone interview was conducted using a scripted program in Microsoft Access. This program ensured that the data were collected and entered appropriately. Prompts were provided to the interviewers, enabling them to ask the questions in the same manner. Finally, the program contained decision trees that proceeded based on the mother's response, again ensuring that the interviewers asked all of the relevant questions for each interview. By entering the data directly into the computer during the interview, data entry errors were significantly reduced. If there was a technical problem, data could later be retrieved from the tape recordings and re-entered into the computer.

Due to the large geographic region included in this study (the state of Florida), telephone interviews were selected as a more feasible methodology compared to face-to-face interviews or mailed, self-administered questionnaires. Multiple studies have found that response rates are similar for telephone and face-to-face interviews, while usually achieving higher response rates and more complete responses than mailed questionnaires (Aneshensel, Frerichs, Clark, & Yokopenic, 1982; McCormick, Workman-Daniels, Brooks-Gunn, & Peckham, 1993; O'Toole, Battistutta, Long, & Crouch, 1986). In addition, the quality of data gathered by telephone interviews is comparable to face-to-face interviews in terms of reliability and validity (Bauman, 1993; McCormick et al., 1993; O'Toole et al., 1986), while telephone responses have been found to have fewer omissions and be more reliable and valid than mailed questionnaires (Fournier & Kovess, 1993; Hinkle & King, 1978; O'Toole et al., 1986). Telephone interviews have been reported as sensitive to detecting depression using both the Center for Epidemiological



Studies – Depression Scale (CES-D; Aneshensel et al., 1982) and Diagnostic Interview Schedule (Wells, Burnam, Leake, & Robins, 1988). Finally, telephone interviews have successfully been used with sensitive populations (Fenig, Levav, Kohn, & Yelin, 1993) and when asking personal and/or health related questions (McCormick et al., 1993; O'Toole et al., 1986; Weeks, Kulka, Lessler, & Whitmore, 1983).

### Structured Interview and Questionnaires

#### Demographics

Demographic information was obtained from the camp application or the first interview. Demographic variables related to the child included age, sex, race, illness diagnosis, time since diagnosis (disease duration), and previous camp experience at BCGC. Maternal demographic variables included age, race, marital status, employment status, number of other children in the home, years of education, and annual household income. Finally, mothers were asked to estimate the percent of time they considered themselves to be the primary caregiver.

#### Objective Stress

A structured interview assessed the objective stress related to caring for a child with a chronic physical condition, including medications, home medical procedures, medical care outside of home, and nighttime medical care. Objective stress was assessed during the pre-camp, post-camp, and follow-up interviews. Objective stress was not assessed while the child was at camp (during-camp interview). As the child was not in the home during camp, the mother was not required to care for the child's medical needs, thus objective stress was assumed to be zero.

All questions about objective stress asked the mother to describe the frequency and duration for each area of medical care. As medication regimens and home care procedures can be complex, we focused only on what mothers were required to do yesterday, assuming this was an accurate reflection of what they did every day. Interviews focusing on specific behaviors during a time-limited period (e.g., previous 24 hours) has been shown to be an effective way to assess behavior (Johnson, 1995; Quittner, Opiari, Regoli, Jacobsen, & Eigen, 1992). As medical appointments and nighttime care are less frequent caregiving events, mothers were asked to recall these events for the previous week.

The following is an example of how the interview was conducted. A mother was asked if her child took medications yesterday. If she said yes, she was asked how many times (frequency). Then, for each time the mother was involved with giving the child medications, she was asked how long did it take to give the medications (duration). Composite scores for both the frequency and the duration of caregiving activities were calculated using all four areas of medical care (a detailed description of the composite scores calculation is presented in the results section).

Medications and home medical procedures were assessed in terms of the mothers' involvement with the child's medication regimen and/or medical procedures (e.g., flushing a central line or peak flow meter monitoring). Medical care outside the home included doctor appointments, medical treatments like chemotherapy or physical therapy, waiting room time, and time spent traveling to and from such medical care. Nighttime care was measured in terms of disruptions to a mother's sleep in order to care for her



child's medical needs, and included time spent caring for the child and time required to fall asleep again. See Appendix A for a complete outline of the interview.

### Subjective Stress

A structured interview also assessed subjective stress in terms of maternal perception of caregiver stress (see Appendix A). Caregiving stress questions asked mothers to rate their perceived stress level associated with each of the caregiving tasks (medications, home care procedures, medical appointments, and nighttime care). For example, after the mother estimated the amount of time required to give her child medications, she was asked how stressful that situation was for her on a 4-point likert scale, with zero being not at all stressful and four being extremely stressful. Subjective stress was measured as part of the pre-camp, post-camp, and follow-up interviews. Similar to objective stress, since the mother was not required to care for her child while the child was at camp, subjective stress was assumed to be zero at the during-camp interview and was not measured.

### Outcomes

The following four measures were given as part of the structured telephone interview at all four assessments (pre-camp, during camp, post-camp, and follow-up).

### Overload

Four items, developed by Pearlin et al. (1990), were used to assess caregiver overload in terms of burnout, fatigue, and the relentless nature of caring for a person with a chronic condition. This measure, which has previously been used with caregivers of patients with Alzheimer's disease, was administered during all four interviews. In this study, we examined the reliability at each interview time and the coefficient alphas

ranged from .75 to .83, with an average of .78, demonstrating adequate reliability. See Appendix B for scale items.

#### Depression-Anxiety

Six items, a subset of a 22-item screening inventory (Crandell & Dohrenwend, 1967), was used to ask mothers about nervousness, low spirits, feelings of isolation, restlessness, worry, and the inability to take care of things because "you can't get going" (Breslau et al., 1982). This scale was administered at all four interviews. Internal consistency was adequate for this sample, with the reliabilities from each interview ranging from .64 to .77, with an average coefficient alpha of .72. Items are presented in Appendix B

#### Maternal Distress

A seven item scale, developed by Pearlin and Schooler (1978), assessed the distress directly related to being a parent during all four interviews. This measure has been used with mothers of children with CF, cerebral palsy, spina bifida, and physical handicaps (Breslau et al., 1982), and demonstrated good reliability in this study (alphas range .82 to .89, average alpha = .86). See Appendix B for scale items.

#### Recreational Activities

The Recreational Activities Checklist (RAC), designed for this study, is based on the Interactions with Environment Checklist (Smith, Gottlieb, Gurwitsch, & Blotcky, 1987) and the Daily Activity Log (Quittner et al., 1992). The scale consisted of 25 leisure time and non-work-related activities, with the subject responding to the amount of time they participated in these activities during the previous week. Time spent in recreational activities was assessed during all four interviews. Scores were obtained by summing the amount of time spent in recreational activities. See Appendix C for scale items.

### Time Demands

The Excess Time Demands Scale is a 14-item questionnaire that measures the degree to which caring for a child with a disability interferes with a mother's time for herself and others (Holroyd, 1987). Mothers respond to questions in a true/false format. In the current study, this measure demonstrated adequate reliability (pre-camp  $\alpha = .71$  and follow-up  $\alpha = .75$ ). Due to the fact that this scale measures more stable phenomenon (e.g., I have had to give up a job to care for my child), it was not expected to change after a short period of time (i.e., one week). Thus the Time Demands Scale was given only as part of the first (pre-camp) and last (follow-up) structured telephone interview. See Appendix B for scale items.

Table 1: Demographic Characteristics of the Study Sample

	Percent	Mean	SD	Range
<u>CHILD VARIABLES</u>				
Child Sex				
Male	48			
Female	52			
Child Race				
Caucasian	68.2			
African-American	17.3			
Hispanic	7.8			
Other	6.7			
Illness Group				
Cancer on Treatment	12.8			
Cancer Not on Treatment	15.6			
Epilepsy	28.5			
Kidney	15.6			
Asthma	27.4			
Child's Current Age (years)		11.65	2.56	6.5 - 17
Disease Duration (years)		6.8	4.4	0.35 - 17
≤ 2 years	83.2			
> 2 years	16.8			
Camp Experience (years)		0.75	0.99	0 - 4
<u>MOTHER VARIABLES</u>				
Maternal Race				
Caucasian	72.6			
African-American	17.3			
Hispanic	8.4			
Other	1.7			
Marital Status				
Married	66.5			
Divorced	11.2			
Single	19.0			
Widow	2.2			
Other	1.1			
Employed				
Yes	65.4			
No	34.6			
Number of Other Children in Home		1.01	0.69	0-3
Maternal Age		39.21	6.28	26.5-55.3
Maternal Education (years)		13.9	2.32	5 - 20
Annual Household Income		50,477	49,230	3000 - 400,000
Caretaker Time (percent)		84.32	17.27	45 - 100

Table 2: Means, Standard Deviations, and Significant Group Differences for Illness Groups and Demographic Variables

	Mean	SD	Range
Child's Age (years)			
Cancer on Treatment	9.79 <sup>a,b,c</sup>	1.95	6.5 - 15.0
Epilepsy	13.23 <sup>a,d</sup>	2.51	8.2 - 17.0
Kidney	12.57 <sup>b,e</sup>	2.36	7.6 - 16.2
Asthma	10.47 <sup>d,e,f</sup>	1.37	7.6 - 12.7
Cancer Not on Treatment	11.46 <sup>c,f</sup>	2.56	6.5 - 17.0
Duration of Disease (years)			
Cancer on Treatment	2.61 <sup>a,b,c</sup>	2.33	.35 - 8.6
Epilepsy	8.99 <sup>a,d</sup>	4.63	.42 - 17.0
Kidney	8.21 <sup>b,e</sup>	4.92	.51 - 16.2
Asthma	7.64 <sup>c,f</sup>	2.91	1.7 - 12.7
Cancer Not on Treatment	3.41 <sup>d,e,f</sup>	2.33	.51 - 10.77
Previous Camp Experience (years)			
Cancer on Treatment	0.52	.73	0 - 2
Epilepsy	1.02 <sup>a</sup>	1.30	0 - 4
Kidney	0.89	1.07	0 - 4
Asthma	0.37 <sup>a,b</sup>	.53	0 - 2
Cancer Not on Treatment	1.00 <sup>b</sup>	.86	0 - 2
Maternal Age (years)			
Cancer on Treatment	35.52 <sup>a,b</sup>	4.91	28.2 - 49.6
Epilepsy	40.88 <sup>a</sup>	7.04	28.3 - 54.8
Kidney	40.29 <sup>b</sup>	6.23	27.7 - 52.5
Asthma	39.12	6.13	26.5 - 55.3
Cancer Not on Treatment	38.28	4.85	27.3 - 46.5

Note. Means sharing superscripts within each variable are significantly different ( $p < .05$ ).

Table 3: Mean and Standard Deviations for Attrition and Missing Data

	Mean	SD	Range
Camp Experience (years)			
Completed two or more interviews	0.80	1.02	0 - 4
Completed only pre-camp interview	0.39	.61	0 - 1
Annual Household Income			
Completed two or more interviews	52,171	51,033	3,000 - 400,000
Completed only pre-camp interview	35,768	25,771	6,000 - 88,000
Caretaker Time (percent)			
Completed two or more interviews	83.43	17.47	45 - 100
Completed only pre-camp interview	92.22	13.20	80 - 100
Caregiving Frequency			
Completed two or more interviews	16.30	15.02	0 - 99
Completed only pre-camp interview	10.39	9.22	1 - 28
Caregiving Stress			
Completed two or more interviews	9.22	16.56	0 - 92
Completed only pre-camp interview	2.89	4.63	0 - 14

Note. Means for each variable significantly different ( $p < .05$ ).

For all variables except Annual Household Income,  $\underline{n}$  = 161 for completed two or more interviews and  $\underline{n}$  = 179 for completed only pre-camp interview.

Due to missing data, Annual Household Income  $\underline{n}$  = 139 for completed two or more interviews and  $\underline{n}$  = 155 for completed only pre-camp interview.

## RESULTS

All analyses were conducted using SPSS 8.0 statistical software package.

### Preliminary Analyses

#### Objective Stress Calculations and Related Descriptive Statistics

Two composite scores of objective stress were derived from the structured interview: caregiving frequency and caregiving duration.

Caregiving Frequency. Medication and in-home medical care were measured in terms of frequency per day, while out-of-home medical care and nighttime care were measured in terms of frequency per week. Thus the following equation was used to create a composite score for each subject, with total caregiving frequency reported as number of caregiving activities performed per week:

Weekly Caregiving Frequency = 7(frequency of daily medications) + 7(frequency of daily in-home care activities) + frequency of out-of-home care activities + frequency of nighttime care

The caregiving frequency composite score means and standard deviations for the total sample and each illness group are presented in Table 4. On average, the mothers in this study engaged in almost 16 medically related caregiving activities per week, yet there was considerable variability based on the child's illness. For example, mothers of children with kidney disorders performed an average of 24 caregiving activities per week while mothers of children with cancer not on treatment performed an average of five to six caregiving activities per week.

A one-way ANOVA was conducted to compare illness group differences in caregiving frequency. Significant between illness group differences were found for caregiving frequency,  $F(4, 174) = 6.42, p < .01$ . Post-hoc analyses using the Tukey HSD test suggest that mothers of children with cancer not on treatment participate in significantly fewer caregiving activities ( $M = 5.50$ ) than mothers of the other illness groups ( $M$ s ranged from 15.82 to 24.00).

Caregiving Duration. Medication and in-home medical care were measured in terms of minutes per day, while out-of-home medical care and nighttime care were measured in terms of minutes per week. A composite score for caregiving duration per week was calculated using the following equation, with total caregiving duration reported as hours per week:

$$\text{Weekly Caregiving Duration} = (7(\Sigma \text{ duration of daily medications}) + 7(\Sigma \text{ duration of daily in-home care activities}) + \Sigma \text{ duration of out-of-home activities} + \Sigma \text{ duration of driving time round-trip for out-of-home activities} + \Sigma \text{ duration of time caring for child during night} + \Sigma \text{ duration of time to fall back asleep after caring for child during night}) / 60$$

The weekly duration composite score means and standard deviations for the total sample and each illness group are presented in Table 4. On average, mothers were spending approximately three hours per week on medically related caregiving activities. The range was from less than two hours for mothers of children with epilepsy to five and a half hours for mothers of children with cancer on treatment.

A one-way ANOVA was conducted to compare illness group differences in caregiving duration. A significant between illness group difference was found for caregiving duration,  $F(4, 174) = 5.23, p < .01$ . Post-hoc analyses using the Tukey HSD suggested that caregiving duration was significantly shorter for mothers of children with



epilepsy ( $\underline{M} = 1.77$ ) and cancer not on treatment ( $\underline{M} = 2.14$ ) than for mothers of children with cancer on treatment ( $\underline{M} = 5.55$ ) or kidney disorders ( $\underline{M} = 5.37$ ). Significant differences are indicated in Table 4.

Caregiving frequency and caregiving duration were significantly correlated ( $r = .50$ ). However, these two variables are believed to represent different concepts in terms of caregiver burden, thus they were not combined as a single indicator of objective stress in this study.

#### Subjective Stress Calculation and Related Descriptive Statistics

During the structured interview, mothers rated how stressful each caregiving activity was for them. A composite score for the amount of stress related to caregiving was calculated using the following equation, which sums the stress values. This results in a total stress score for the previous week:

$$\text{Weekly Caregiving Stress} = 7(\Sigma \text{ stress related to daily medications}) + 7(\Sigma \text{ stress related to daily in-home care activities}) + \Sigma \text{ stress related out-of-home activities/appointments} + \Sigma \text{ stress related to getting up to care for child during night}$$

The weekly caregiving stress composite score mean and standard deviations for the total sample and for each illness group are presented in Table 4. Although mothers engaged in approximately 16 caregiving activities which required approximately three hours per week, their average stress level for the previous week was less than nine, which reflects the fact that mothers reported 59% of their caregiving activities as “not at all stressful” (stress rating of zero). When examining each of caregiving areas, medications and home care procedures were reported as “not at all stressful” more often than nighttime care (see Table 5).

A one-way ANOVA was conducted comparing average caregiving stress for the illness groups. Significant differences in caregiving stress were found for the illness groups,  $F(4, 174) = 3.72, p < .01$ . Post-hoc analyses, using the Tukey HSD test, indicate that the mothers of children with epilepsy ( $M = 3.20$ ) reported significantly less stress related to caregiving activities than mothers of children with cancer on treatment ( $M = 14.22$ ), kidney disorders ( $M = 12.86$ ), or asthma ( $M = 11.37$ ). Mother of children with cancer not on treatment ( $M = 4.64$ ) reported significantly less subjective stress than mothers of children with cancer on treatment and kidney disorders. Significant differences are indicated in Table 4.

#### Calculation of Outcome Variables and Related Descriptive Statistics

##### Overload

A total overload score was calculated by summing the responses on this scale (see Appendix B). A higher score indicates a higher level of overload in terms of burnout and fatigue related to caregiving.

Welch's t-tests, which correct for unequal sample sizes, were conducted comparing the means of the current sample with a normative population of caregivers of Alzheimer's disease (Pearlin, Mullan, Semple, & Skaff, 1990). In general, mothers' scores on the overload scale were consistent to the normative population of caregivers of Alzheimer's disease (see Table 6). However, mothers of children with cancer on treatment scored significantly higher than the normative group of AD caregivers, suggesting that mothers of children with cancer on treatment experience greater feelings of burnout and fatigue related to caregiving than do caregivers of AD patients.

### Depression-Anxiety

Items on this measure were scored one for a yes response and zero for a no response. On item two, "low spirits" and "very low spirits" were scored as one and "very good spirits" and "good spirits" were scored as a zero. Scores were summed to obtain an overall depression-anxiety score. Higher scores suggest more symptoms of depression and anxiety.

Welch's t-tests were conducted comparing the mean depression-anxiety scores for the current sample with a normative population of mothers of children without a chronic illness and mothers of children with myelodysplasia, a chronic blood disorder that is managed by transfusions and antibiotics (Breslau, Staruch, & Mortimer, 1982). Mothers in nearly all illness groups reported significantly greater depression-anxiety compared to mothers of children without a chronic illness (see Table 6). Only mothers of children with asthma did not. However, significant differences in depression-anxiety scores were not found between the current sample and mothers of children with myelodysplasia.

### Maternal Distress

A total maternal distress score was calculated by summing the responses on this scale (see Appendix B). A higher score indicates a higher level of stress related to being a parent.

Welch's t-tests were conducted comparing the mean maternal distress scores for the current sample with a normative population of mothers of children without a chronic illness and mothers of children with myelodysplasia (Breslau et al., 1982). Mothers in the current study reported significantly higher maternal distress compared to a normative population of mothers whose children do not have a chronic illness (see Table 6).

However, maternal distress scores for mothers in the current study were not significantly different from mothers of children with myelodysplasia.

Relationship Between the Psychological Distress Measures. Pearson correlations were used to examine the relationship between the three measures of psychological distress (overload, depression-anxiety, maternal distress). Overload correlated moderately with both depression-anxiety ( $r = .44$ ) and maternal distress ( $r = .48$ ), while there was a stronger correlation between depression-anxiety and maternal distress ( $r = .64$ ). However, an examination of the individual items for each of these scales suggests that they tap different concepts (see Appendix B). Consequently, each was treated as a separate outcome variable. The analyses were also run combining the measures into a single indicator of distress; no additional effects emerged and several of the effects found using the individual measures were lost. Therefore, the analyses using each measure as an independent outcome variable are reported here.

#### Recreational Activities Checklist (RAC)

The RAC yielded a duration score by summing the amount of time (number of total hours) subjects spent in recreational activities during the previous week. Mothers spent an average of 36 hours per week in recreational activities. However, there was significant variability in the amount of time spent in recreational activities.

#### Time Demands

Items on this measure were scored one for a true response and zero for a false response. Reverse scored items (#s 3, 5, 8, 13) were scored one for a false response and zero for a true response. Scores were summed to obtain an overall time demands score, with higher scores suggesting strong maternal perceptions that the child's illness interferes with a mother's time for herself and her family.

T-tests were conducted comparing the mean time demands scores for the current sample with a normative population of mothers of children without a chronic illness and mothers of children with cystic fibrosis (Quittner et al., 1992). Mothers of children with cancer on treatment, epilepsy, and kidney disease reported significantly greater time demands than both mothers of children without a chronic illness as well as mothers of children with cystic fibrosis (see Table 6).

### Cross-Sectional Analyses (Pre-Camp)

Approach to Model Testing. Each part of the proposed caregiver burden model was tested using hierarchical multiple regression analyses. This approach allowed us to examine the predictors of each part of the model. For all analyses, the first step included all demographic variables (child's sex, child's age, disease duration, previous camp experience, maternal age, maternal marital status, maternal employment status, number of other children in the home, percent time mother served as primary caretaker, maternal race, maternal education, annual household income). Because the large number of demographic variables introduces multicollinearity, any variable with a *p*-value of .30 or less was retained for the next step.

Because the literature suggests that the psychosocial effects of the diagnosis of a chronic illness can last for up to two years (Grey, Lipman, Cameron, & Thurber, 1997; Jacobson et al., 1990; Kovacs et al., 1990; Phipps, Fairclough, & Mulhern, 1995), we elected to treat disease duration as a two-level ordinal variable (disease duration  $\leq 2$  years versus  $> 2$  years). Although two-level ordinal effects are presented below, we did re-examine the data using disease duration as a continuous variable; no additional disease duration effects emerged and some of the two-level ordinal effects were lost.

Maternal race was initially entered as separate categorical variables (African-American, Hispanic, Asian-American, other) with Caucasian serving as the comparison group. However, other than African-American, no other race was a significant predictor of any variable. Thus race was collapsed into two variables, African-American and Minority, with Caucasian serving as the comparison group for both variables.

The second step for all analyses consisted of the illness groups, which were entered as separate categorical variables, with cancer on treatment serving as the comparison group. Again, any variable with a significance level less than .30 was retained for the next step.

Further steps depended on the hypothesis being tested and are described below. Additional steps were necessary to eliminate variables that were not significant as well as enter the independent variables being tested. The statistical values for the regression models which best predicted the dependent variable are reported in Tables 7-13.

*1. Demographic variables will predict objective stress.*

For this analysis, the frequency and duration of caregiving activities served as the dependent variable in two separate analyses. Child's age, illness group, disease duration, and single parent status were expected to predict objective stress (frequency and duration of caregiving activities).

For the caregiving frequency analysis, demographic and illness group variables were entered in the first two steps, and the third step was used to refine the model. Variables were eliminated from Step 3 if  $p > .05$  (see Table 7). Illness group was confirmed to be a significant predictor of caregiving frequency, with mothers in all illness groups engaging in more frequent caregiving tasks than mothers of children with cancer



not on treatment (see Table 4 for means). Child's sex was an unexpected predictor of caregiving frequency, with mothers of male children performing more caregiving tasks ( $M = 18.5$ ) than mothers of female children ( $M = 13.2$ ).

For the caregiving duration analysis, demographics and illness group variables were entered in the first two steps. Steps 3-6 were used to refine the model. Because the large number of variables in Step 3 introduces multicollinearity, values were retained if  $p < .10$ . For Steps 4 and 5 only statistically significant variables ( $p < .05$ ) were retained (see Table 8)

As expected, illness group predicted caregiving duration, with mothers of children with cancer on treatment ( $M = 5.6$ ) and mothers of children with kidney disease ( $M = 5.4$ ) spending more hours in caregiving tasks than mothers of children with cancer not on treatment ( $M = 2.1$ ). Child's sex was an unexpected predictor of duration, with mothers of male children spending more hours in caregiving ( $M = 3.9$ ) than mothers of female children ( $M = 2.4$ ).

## *2. Greater objective stress will be related to greater subjective stress.*

As greater objective stress places an increased demand on a mother's time and attention, it was expected that mothers who reported a greater frequency and duration of objective stress would also report greater subjective stress (perception of stress related to caregiving activities). Thus subjective stress was entered as the dependent variable in this model, with frequency and duration of objective stress entered as independent variables in the fourth step (the third step was used to refine demographic and illness group predictors with variables eliminated if  $p < .10$ ). The final model accounted for 26% of the variance (see Table 9). As expected, mothers who engaged in more



caregiving activities and spent more time caring for their child perceived greater stress related to caregiving. In addition, mothers of children with cancer on treatment ( $\underline{M} = 14.2$ ) and mothers of children with asthma ( $\underline{M} = 11.4$ ) reported more caregiving stress than mothers of children of cancer not on treatment ( $\underline{M} = 4.64$ ). Finally, maternal race was an unexpected predictor of caregiving stress, with African-American mothers reported more caregiving stress ( $\underline{M} = 15.1$ ) than Caucasian mothers ( $\underline{M} = 7.2$ ).

### *3. Greater objective stress will predict greater negative outcomes.*

The proposed caregiver burden model suggests that objective stress has a direct effect on outcomes. Thus, it was expected that mothers who reported greater objective stress (frequency and duration of caregiving activities) would also report more overload, more depression-anxiety, more maternal distress, and less recreational activity time. Thus the outcome variables (overload, depression-anxiety, maternal distress, and recreational activity time) were entered as the dependent variable in four separate regression models, with objective stress (frequency and duration of caregiving activities) entered as independent variables in the third step for each model (see Tables 10-13). For some models, a fourth and fifth step were necessary to eliminate variables that were not significant. Elimination criteria are described for each variable.

Neither caregiving frequency nor caregiving duration predicted overload scores (see Table 10). For depression-anxiety, using the  $p < .30$  criterion for the elimination of variables (due to the large number of variables), caregiving duration was still considered a possible predictor of depression-anxiety in Step 3. However, when entered into Step 4, caregiving duration remained a non-significant predictor (see Table 11). For maternal

distress, caregiving frequency was carried into Step 4 (see Table 12). However, neither caregiving frequency nor caregiving duration predicted maternal distress.

For recreational activity time, a marginal effect ( $p = .08$ ) was found, suggesting that caregiving frequency approached significance as a predictor of the amount of time spent in recreational activities. Mothers who reported performing fewer caregiving activities spent more time in recreational activities (see Table 13). Maternal employment status and disease group were unexpected significant predictors of recreational activity time in the final objective stress model. Mothers who were not employed spent more hours during the previous week in recreational activities ( $M = 41.3$ ) than employed mothers ( $M = 33.6$ ). Mothers of children with asthma spent more hours during the previous week in recreational activities ( $M = 44.1$ ) than mothers of children from the other illness groups ( $M$ s range 28.2 – 37.8).

#### *4. Greater subjective stress will predict greater negative outcomes.*

The proposed caregiver burden model suggests that an indirect effect occurs through the impact of subjective stress on outcomes. Therefore, it was expected that mothers who reported greater stress related to caregiving activities (caregiving stress) would also reporting greater psychological distress and less time spent in recreational activities. Thus, the outcome variables (overload, depression-anxiety, maternal distress, and recreational activity time) were entered as the dependent variable in separate models, with caregiving stress (perception of stress related to caregiving activities) entered as the independent variable in each regression model.

Caregiving stress was entered in Step 4 for overload, along with the demographic variables that were retained from Steps 1 and 2. Variables were retained for Step 5 if  $p <$

.10 and for Step 6 if  $p < .05$  (see Table 10). The final overload model accounted for 9% of the variance. As expected, caregiving stress significantly predicted overload, suggesting that mothers who perceived greater levels of stress directly related to caregiving activities also perceived greater feelings of overload. In addition to caregiving stress, the final model for overload also included the percent of time mothers perceived themselves to be the primary caretaker, with mothers who reported a higher percent of caretaker time also reporting more overload.

Caregiving stress was entered in the fifth step of the depression-anxiety analysis, with only variables that were statistically significant ( $p < .05$ ) retained for the next step. The final model for depression-anxiety scores accounted for 12% of the variance (see Table 11). Caregiving stress significantly predicted depression-anxiety scores, supporting the hypothesis and suggesting that mothers who perceived greater stress related to caregiving activities also reported greater depression-anxiety. Unexpected predictors of depression-anxiety included maternal employment status and maternal race. Mothers who were not currently employed reported greater depression-anxiety scores ( $M = 2.4$ ) than mothers who were currently employed ( $M = 1.9$ ), while African-American mothers reported greater depression-anxiety scores ( $M = 2.6$ ) than Caucasian mothers ( $M = 1.9$ ).

For the maternal distress analysis (Table 12), caregiving stress was entered in Step 5, with variables retained for Step 6 using the more generous cutoff of  $p < .30$ . As multiple variables approached significance in Step 6, variables were retained for Step 7 if  $p < .05$ . Only statistically significant variables ( $p < .05$ ) were retained in additional steps. Although maternal African-American race was not included in the final model, it should

be noted that in Step 8 this variable continued to approach significance. In the final model for maternal distress, accounting for 13.5% of the variance, caregiving stress predicted maternal distress, as expected. Illness group was an unexpected predictor of maternal distress, with mothers of children with asthma reporting lower distress related to being a parent ( $M = 14.6$ ) than mothers of children in the remaining illness groups ( $M$ s range 16 – 17.5).

Caregiving stress was entered in Step 6 of the recreational activity time analysis. As caregiving stress approached significance ( $p = .09$ ) it was retained for the next step, while variables with a p-value greater than .10 were eliminated. The final model, accounting for 6% of the variance, is presented in Table 13. Along with subjective stress, time spent in recreational activities was also predicted by employment status and illness group. Mothers who were not employed spent more hours during the previous week in recreational activities ( $M = 41.3$ ) than employed mothers ( $M = 33.6$ ), while mothers of children with asthma spent more hours during the previous week in recreational activities ( $M = 44.1$ ) than mothers of children from the other illness groups ( $M$ s range 28.2 – 37.8).

#### *5. Subjective stress mediates the relationship between objective stress and outcomes*

In order to test the mediator model, there needed to be a significant relationship between the components of the model (objective stress predicted greater negative outcomes, objective stress predicted greater subjective stress, and subjective stress predicted greater negative outcomes). This criterion was not met for any of the outcome measures. However, as there was a trend suggesting that caregiving frequency predicted time spent in recreational activities, we proceeded to test the mediator hypothesis. Recreational activity time served as the dependent variable in the mediator model, with

frequency of caregiving tasks, an objective stressor, entered first. Next, subjective stress (perception of stress related to caregiving) was added to the regression equation. The mediator model would have been supported if the regression coefficients for the objective stress (frequency) decreased once subjective stress was added to the model.

However, as seen in Table 13 (Step 8), there was no strong support for the mediator model. When caregiving stress was added to the model, both caregiving frequency and caregiving stress became non-significant due to multicollinearity.

### Longitudinal Analyses

Repeated measures ANCOVAs were used to examine changes in objective stress, subjective stress, and outcome variables over time. For all analyses, illness group was the between subjects variable while time was the repeated measure variable. As significant differences between illness groups were found for child's age, disease duration, previous camp experience, and maternal age, these variables were entered as covariates in each ANCOVA. Child's age was a significant covariate in the maternal distress ANCOVA. However, child's age did not substantially improve the within group variance ( $MS_w = 8.4$  with the covariate,  $MS_w = 8.6$  without the covariate), therefore the covariate was eliminated from the maternal distress analysis (Hair, Anderson, Tatham, & Black, 1998). No significant relationships between the covariates and the dependent variables were found for the rest of the analyses, thus the covariates were not used and repeated measures ANOVAs were performed (Weinfurt, 1995). The final ANOVA models can be seen in Table 14, with adjusted means and standard deviations reported in Table 15.

*1. Objective stress, which is assumed to decrease while the child is at camp, will remain at baseline levels one week and one month post-camp.*

As respite care is only a short term break from caregiving, and the child's illness required caregiving after camp, objective stress was not expected to change after the child returned home from camp. A 5 (illness group) x 3 (time) mixed-model ANOVA examined caregiving frequency for the illness groups over time (see Table 14). Contrary to the hypothesis, a significant interaction between illness group and time was found for caregiving frequency,  $F(8, 312) = 2.24, p = .03$ , suggesting that caregiving frequency changed over time differently for each of the illness groups (see Table 15 for means). Notably, caregiving frequency increased for mothers of children with asthma while it decreased for the other illness groups.

A 5 (illness group) x 2 (time) mixed-model ANOVA was conducted comparing caregiving duration between the illness groups over time (see Table 14). As expected, there was no significant main effect of time for duration of caregiving activities,  $F(2, 312) = .94, n.s.$  However, a significant main effect was found for illness group,  $F(4, 156) = 7.43, p < .01$ . Post-hoc analyses using Tukey's HSD found that regardless of time, mothers of children with cancer on treatment spent more hours in caregiving activities than mothers of children with epilepsy, asthma, or cancer not on treatment (see Table 15 for means). Mothers of children with kidney disorders spent more time in caregiving activities than mothers of children with epilepsy regardless of time.

*2. Removing the objective stress related to caring for a child with a chronic illness will reduce subjective stress after camp, with changes maintained at least one week post-camp, and up to one month post-camp.*

Although objective stress was not expected to change, it was hypothesized that a week of respite care would decrease mothers' perceptions of stress related to caregiving after her child returned home from camp. To examine this hypothesis, a 5 (illness group)



x 2 (time) mixed-model ANOVA was conducted (see Table 14). Contrary to the hypothesis a main effect for time was not found,  $F(4, 156) = .84$ , n.s. However, a significant main effect for illness group was found,  $F(4, 156) = 4.08$ ,  $p < .01$ . Post-hoc analyses using Tukey's HSD suggest that mothers of children with kidney disorders and asthma perceive significantly greater stress than mothers of children with epilepsy, regardless of time.

*3. Removing the objective stress related to caring for a child with a chronic illness will reduce psychological distress during camp, with changes maintained at least one week post-camp, and up to one month post-camp.*

A 5 (group) x 4 (time) mixed-model ANOVA was conducted to examine group differences over time for overload (see Table 14). A significant interaction between illness group and time was found for overload,  $F(12, 414) = 1.88$ ,  $p = .04$ , suggesting that reported feelings of overload related to caregiving changed over time differently for each illness group. As seen in Figure 2, overload decreased for all groups while the child was at camp, with reported overload increasing again one week after the child returned home. However, with the exception of the kidney disorders group, overload remained below baseline levels both one week and one month after the child returned home from camp (see Table 15 for means).

A main effect for time was also found for overload,  $F(3, 414) = 24.61$ ,  $p < .01$ . Paired t-tests comparing all time points, collapsed across group, indicate that overload was significantly lower during camp, and remained below baseline levels one week and one month after camp (see Table 16). This suggests that camp provided respite care by reducing the feelings of overload that result from being a caregiver while the child was at camp, with the effect lasting for up to one month after the child returned home from camp.



A 5 (group) x 4 (time) mixed-model ANOVA was conducted to examine group differences over time for depression-anxiety (see Table 14). As expected, a significant main effect for time was found for depression-anxiety,  $F(3, 414) = 4.95, p < .01$  (see Figure 3). Paired t-tests comparing all time points, collapsed across group, indicate that depression-anxiety was significantly lower at the during camp interview ( $M = 1.63$ ) than the pre-camp interview ( $M = 2.09$ ). However, this change in depression-anxiety did not remain significantly below baseline levels one week or one month after camp ended (see Table 17). The reduction in depression-anxiety scores during camp supports the hypothesis that camp provides respite care, although the benefit of the respite care (reducing depression-anxiety) was not maintained after the child returns home from camp.

A 5 (group) x 4 (time) mixed-model ANOVA was conducted to examine group differences over time for maternal distress (see Table 14). A significant interaction between illness group and time was found for maternal distress,  $F(12, 414) = 3.12, p < .01$ , suggesting that maternal distress changed over time differently for each illness group. As seen in Figure 4, this is most notable for the cancer not on treatment group, whose reported levels of maternal distress significantly decreased while the child was at camp, with this change maintained one week and one month after the child returned home from camp. In addition, although the kidney disorders group reported levels of maternal distress decreased while the child was at camp, distress increased to just above baseline level one week post-camp and maintained at this level one month post camp (see Table 15 for means). Respite care appears to provide an immediate effect for all groups,

with scores below baseline up to one month after camp for mothers of children with cancer, both on and off treatment.

There was a significant interaction between time and illness group for time spent in recreational activities,  $F(12, 414) = 1.77, p = .05$ , again suggesting that the amount of time spent in recreational activities varied over time for each illness group. As expected, time spent in recreational activities increased during camp, but only for mothers of children with cancer on treatment and kidney disease. As seen in Figure 5, over time, each illness group's time spent in recreational activities changed in a different pattern. For example, one week after camp, mothers of children with kidney disease reported a sharp decline in time, returning to above baseline levels one month after camp. On the other hand, mothers of children with epilepsy spent less time in activities during and one week after camp, and remained below baseline levels one month after camp ended. Although respite care appears to effect time spent in recreational activities, this effect differs for each illness group, with some mothers engaging in fewer activities during camp while others spent more time in activities while their child was away at camp.

#### Longitudinal Analyses by Illness Group

Significant main effects of illness group were found for each of the three caregiver burden variables (caregiving frequency, caregiving duration, and caregiving stress), suggesting that caregiver burden differs by illness group. In addition, significant interactions between illness groups and time were found for overload, maternal distress, and recreational activity time. However, the benefits of respite care appear to differ depending on the child's illness, and are inconsistent for the different measures.

Therefore, it is important to examine the pattern of results and how the variables relate to one another over time for each illness group.

Two doubly multivariate repeated measures MANOVAs were performed for each illness group: a 3 (time) x 3 (caregiver burden variables) MANOVA was conducted to examine the relationship between caregiving frequency, caregiving duration, and caregiving stress; a 4 (time) x 4 (outcome variables) MANOVA was performed to examine the relationship between overload, depression-anxiety, maternal distress and recreational activity time.

However, as all of the measures have different scales, in order to be able to examine the pattern of results, each of the seven variables were standardized into  $z$ -scores (for each variable,  $M = 0$ ,  $SD = 1$ ). For each variable, this was accomplished by using the pre-camp mean and standard deviation for only one illness group. For example, frequency scores for the asthma group were standardized using the pre-camp frequency mean and standard deviation for the asthma group. This approach also allowed for a visual examination of the relationship between changes in the caregiver burden variables and the outcome variables for each disease group. MANOVAs are presented in Table 18 and adjusted means and standard deviations are presented in Table 19.

### Cancer on Treatment

A 3 (time) x 3 (caregiver burden variables) MANOVA found no significant effects for mothers of children with cancer on treatment (see Table 18). However, power is an issue for this group ( $n = 20$ ) and we believed that the relationship between these variables over time may be derived from an inspection of the means (see Figure 6). These results suggest that although caregiving duration increased one week post-camp, caregiving stress decreased one week post-camp.

For the outcome variables, a 4 (time) x 4 (outcome variables) MANOVA found a significant main effect for both time,  $F(3, 15) = 3.83, p = .03$  and outcome variables,  $F(3, 15) = 4.58, p = .02$ . As seen in Figure 6, overload and depression-anxiety scores decreased while the child was at camp, with both scores remaining below baseline levels one week and one month after the child returned home from camp. However, maternal distress increased while the child was at camp and then decreased to below baseline levels one week and one month after camp. As expected, recreational activity time increased while the child was at camp, with recreational activity time remaining above baseline levels for up to one month after camp ended.

### Epilepsy

A 3 (time) x 3 (caregiver burden variables) MANOVA found an interaction between time and caregiver burden variables which approached significance,  $F(4, 42) = 2.25, p = .08$ . This suggests that the measures changed differently over time for mothers of children with epilepsy. Contrary to the hypothesis that caregiving frequency and duration would not change after camp, caregiving frequency was below baseline one week after camp and remained below baseline up to one month after camp. Caregiving duration was above baseline one week after camp and then returned to near baseline levels one month after camp (see Figure 6). In addition, the related caregiving stress increased one week after camp and maintained above baseline one month after camp.

A significant main effect for outcome variables was found for the 4 (time) x 4 (outcome variables) MANOVA,  $F(3, 40) = 8.12, p < .01$ , suggesting that in general the outcome measures differ from one another. However, Figure 7 shows that the psychological distress variables (overload, depression-anxiety, and maternal distress) followed the expected pattern of change over time, decreasing while the child was at

camp, and remaining below baseline levels up to one month after camp. Although not expected, recreational activity time also decreased during camp, and remained below baseline levels up to one month after camp.

### Kidney

No significant results were found for the 3 (time) x 3 (caregiver burden variables) MANOVA (see Table 18). However, power is an issue for this group ( $n=22$ ), thus it is important to inspect the means for a relationship between these variables over time. Figure 8 demonstrates that caregiving frequency and duration was below baseline both one week and one month after camp, while caregiving stress maintained one week after camp and then decreased to below baseline one month after camp. However, these changes are very small.

Similarly, no significant effects were found for the 4 (time) x 4 (outcome variables) MANOVA (see Table 18). An examination of the means for the three psychological distress variables (overload, depression-anxiety, and maternal distress) indicates that all three variables decreased while the child was at camp, returning to near baseline levels one week after camp. In addition, time spent in recreational activities increased while the child was at camp, decreased one week after camp, and increased to above baseline levels again one month after camp.

### Asthma

No significant results were found for the 3 (time) x 3 (caregiver burden variables) MANOVA (see Table 18). However, Figure 9 suggests that while caregiving frequency increased one week and one month after camp, caregiving duration and caregiving stress maintained near baseline levels over time.

A significant interaction between time and outcome variables was found for the 4 (time) x 4 (outcome variables) MANOVA,  $F(9, 33) = 8.12$ ,  $p = .04$ , suggesting that the outcome variables changed differently over time. Although overload decreased during camp, the other psychological distress variables (depression-anxiety, maternal distress) maintained, with depression-anxiety increasing above baseline one week and one month after camp (see Figure 9). In addition, contrary to expectations, mothers spent less time in recreational activities during camp, as well as one week and one month after camp ended.

#### Cancer Not on Treatment

No significant effects were found for the 3 (time) x 3 (caregiver burden variables) MANOVA (see Table 18). However, power is an issue for this group ( $n = 25$ ). Thus the means were inspected visually (see Table 19). Although caregiving frequency and caregiving duration were above baseline one week after the child returned home from camp, caregiving stress was below baseline levels one week after camp for mothers of children with cancer not on treatment.

The interaction between time and outcome variables approached significance for the 4 (time) x 4 (outcome variables) MANOVA,  $F(9, 13) = 2.53$ ,  $p = .06$ , suggesting that these variables changed differently over time. All three psychological distress variables (overload, depression-anxiety, and maternal distress) were below baseline while the child was at camp, with effects maintained one week after camp. In addition, the changes in overload and maternal distress maintained one month after camp, while depression-anxiety symptoms returned to baseline levels. Contrary to the hypothesis, time spent in recreational activities decreased during camp, increased one week after camp, and decreased again to below baseline levels one month after camp.

Additional Analyses

*The benefits of respite care will generalize to more stable psychological phenomenon (e.g., time demands).*

A 2 (time) x 5 (group) one-way ANOVA was conducted to compare time demands scores over time for the illness groups. A significant main effect of time was found for time demands,  $F(1, 146) = 6.17, p = .01$ . As seen in Figure 11, the perception that caregiving interfered with a mother's time for herself and her family was lower one month after the child returned home from camp compared to one month before the child went to camp. This result is most notable for mothers of children with kidney disorders and cancer not on treatment.



Table 4: Means, Standard Deviations, and Significant Illness Group Differences for Objective and Subjective Stress at Pre-Camp Assessment

	Mean	SD	Range
<b>OBJECTIVE STRESS</b>			
Caregiving Frequency (# events/week)	15.71	14.63	0 – 99
Cancer on Treatment	17.22 <sup>a</sup>	12.06	1 – 52
Epilepsy	15.98 <sup>b</sup>	10.05	0 – 45
Kidney	24.00 <sup>c</sup>	24.27	0 – 99
Asthma	15.82 <sup>d</sup>	12.16	0 – 45
Cancer Not on Treatment	5.50 <sup>abcd</sup>	7.84	0 – 26
Caregiving Duration (# hours/week)	3.13	4.61	0 – 29.15
Cancer on Treatment	5.55 <sup>a,b</sup>	4.57	0 – 18.00
Epilepsy	1.77 <sup>a,c</sup>	3.30	0 – 15.98
Kidney	5.37 <sup>c,d</sup>	7.12	0 – 29.15
Asthma	2.70	3.56	0 – 15.07
Cancer Not on Treatment	2.14 <sup>b,d</sup>	3.79	0 – 16.65
<b>SUBJECTIVE STRESS</b>			
Caregiving Stress (sum of stress/week)	8.59	15.88	0 – 92
Cancer on Treatment	14.22 <sup>a,b</sup>	19.53	0 – 73
Epilepsy	3.20 <sup>a,c,d</sup>	7.36	0 – 29
Kidney	12.86 <sup>c,e</sup>	22.24	0 – 78
Asthma	11.37 <sup>d</sup>	17.07	0 – 92
Cancer Not on Treatment	4.64 <sup>b,e</sup>	10.43	0 – 48

Note. Means sharing superscripts within each variable are significantly different ( $p < .05$ ).

Cancer on Treatment ( $n = 23$ ), Epilepsy ( $n = 51$ ), Kidney ( $n = 28$ ), Asthma ( $n = 49$ ), Cancer Not on Treatment ( $n = 28$ )

Table 5: Percent Of Caregiving Activities Rated As Stressful

Activity and stress rating	Percent
Medications	
Not at all stressful (rating of 0)	68.7
Stressful (rating of 1-4 combined)	31.3
Home Care Procedures	
Not at all stressful (rating of 0)	66.4
Stressful (rating of 1-4 combined)	33.6
Outside Care	
Not at all stressful (rating of 0)	44.6
Stressful (rating of 1-4 combined)	55.4
Nighttime Care	
Not at all stressful (rating of 0)	37.1
Stressful (rating of 1-4 combined)	62.9
Total Caregiving Stress	
Not at all stressful (rating of 0)	59.3
Stressful (rating of 1-4 combined)	40.7

Table 6: Means and Standard Deviations for Illness Groups and Outcome Variables At Pre-Camp Assessment

	Mean	SD	Range
Overload	10.13	3.13	4 – 16
Cancer on Treatment	11.51 <sup>a</sup>	2.92	7 – 16
Epilepsy	10.17	3.14	4 – 16
Kidney	10.00	2.71	5 – 15
Asthma	9.82	3.10	4 – 16
Cancer Not on Treatment	9.57	3.60	4 – 16
<i>Alzheimer's Disease*</i>	10.2 <sup>a</sup>	3.09	
Depression-Anxiety	2.08 <sup>a</sup>	1.55	0 – 6
Cancer on Treatment	2.57 <sup>b</sup>	1.56	0 – 5
Epilepsy	2.14 <sup>c</sup>	1.66	0 – 6
Kidney	2.46 <sup>d</sup>	1.64	0 – 5
Asthma	1.63	1.36	0 – 6
Cancer Not on Treatment	1.96 <sup>e</sup>	1.37	0 – 5
<i>No Illness**</i>	1.40 <sup>abcde</sup>	1.30	
<i>Myelodysplasia**</i>	1.85	1.46	
Maternal Distress	16.10 <sup>a</sup>	4.51	7 – 28
Cancer on Treatment	17.47 <sup>b</sup>	5.01	9 – 28
Epilepsy	16.33 <sup>c</sup>	4.18	8 – 26
Kidney	16.00 <sup>d</sup>	4.67	7 – 24
Asthma	14.64 <sup>e</sup>	4.24	8 – 26
Cancer Not on Treatment	17.14 <sup>f</sup>	4.56	9 – 27
<i>No Illness**</i>	12.90 <sup>abcdef</sup>	4.50	
<i>Myelodysplasia**</i>	15.54	4.69	
Recreational Activities (hrs/week)	36.24	26.43	0.0 – 154.5
Cancer on Treatment	28.22	17.63	1.0 – 66.5
Epilepsy	37.84	27.03	2.2 – 124
Kidney	37.75	19.53	2.5 – 95.58
Asthma	44.12	33.95	2.0 – 154.5
Cancer Not on Treatment	30.62	18.48	0.0 – 72.5

Table 6 – Continued

	Mean	SD	Range
Time Demands	8.59 <sup>ac</sup>	2.60	2 – 14
Cancer on Treatment	9.13 <sup>bd</sup>	2.39	4 – 13
Epilepsy	8.71 <sup>cg</sup>	2.68	2 – 13
Kidney	9.34 <sup>dh</sup>	2.60	3 – 14
Asthma	8.07	2.03	4 – 13
Cancer Not on Treatment	8.07	3.29	2 – 14
<i>No illness</i> ***	7.35 <sup>abcd</sup>	2.59	
<i>Cystic Fibrosis</i> ***	6.80 <sup>efgh</sup>	2.30	

Note. Means sharing superscripts within each variable are significantly different using the Welch's correction for unequal variances ( $p < .05$ ).

Cancer on Treatment (n = 23), Epilepsy (n = 51), Kidney (n = 28), Asthma (n = 49), Cancer Not on Treatment (n = 28)

\*Normative population from Pearlin et al. (1990), n = 555

\*\*Normative population from Breslau et al. (1982), no illness n = 456, myelodysplasia n = 82

\*\*\*Normative population from Quittner et al. (1992), both groups n = 20

Table 7: Hierarchical Multiple Regression Steps: Predictors of Caregiving Frequency

Predictor	B	t	p	Adj. R <sup>2</sup>	F	p
Step 1 - Demographics				< 0.01	0.95	0.51
Child's Sex	-0.19	-2.26	0.03			
Child's Age	-0.03	-0.34	0.73			
Disease Duration $\leq$ 2 years	0.07	0.87	0.39			
Camp Experience	0.10	1.05	0.30			
Maternal Age	0.02	0.18	0.86			
Marital Status	-0.02	-0.22	0.83			
Employed	0.04	0.47	0.64			
# Other Children in Home	0.09	1.00	0.32			
Caretaker Time	-0.04	-0.39	0.70			
Mother African-American	0.19	1.46	0.15			
Mother Non-White Minority	-0.12	-0.98	0.33			
Maternal Education	-0.10	-1.11	0.27			
Annual Household Income	0.04	0.40	0.69			
Step 2 - Illness Group				0.14	4.56	< 0.01
Child's Sex	-0.19	-2.64	0.01			
Camp Experience	0.09	1.23	0.22			
Mother African-American	0.04	0.58	0.57			
Maternal Education	-0.09	-1.22	0.23			
Cancer on Treatment	0.28	3.13	< 0.01			
Epilepsy	0.32	3.27	< 0.01			
Kidney	0.46	5.06	< 0.01			
Asthma	0.31	3.07	< 0.01			
Step 3				0.14	5.18	< 0.01
Child's Sex	-0.19	-2.66	0.01			
Camp Experience	0.09	1.19	0.23			
Maternal Education	-0.09	-1.31	0.19			
Cancer on Treatment	0.27	3.11	< 0.01			
Epilepsy	0.32	3.26	< 0.01			
Kidney	0.47	5.16	< 0.01			
Asthma	0.31	3.11	< 0.01			
Step 4 - Final Model				0.14	6.67	< 0.01
Child's Sex	-0.18	-2.61	0.01			
Cancer On Treatment	0.26	2.99	< 0.01			
Epilepsy	0.32	3.24	< 0.01			
Kidney	0.46	5.10	< 0.01			
Asthma	0.29	2.96	< 0.01			

Note. Higher scores indicate greater caregiving frequency (greater # of caregiving activities)

Table 7 – Continued

The following variables are coded yes = 1, no = 0

Child's Sex coded yes for females

Disease Duration  $\leq 2$  years coded yes if duration was less than or equal to 2 years

Marital Status coded yes if married

Employed coded yes if currently employed

African-American coded yes if African-American

Non-White Minority coded yes if non-white minority (e.g., Hispanic, Asian)

Cancer on Treatment coded yes for child with cancer on treatment

Epilepsy coded yes for child with epilepsy

Kidney coded yes for child with kidney disorder

Asthma coded yes for child with asthma

Camp Experience coded for number of previous years attended BCGC

Caretaker Time coded in percent of time mother considers herself primary caretaker

Table 8: Hierarchical Multiple Regression Steps: Predictors of Caregiving Duration

Predictor	B	t	p	Adj. R <sup>2</sup>	F	p
Step 1 – Demographics				0.05	1.56	0.10
Child's Sex	-0.18	-2.15	0.03			
Child's Age	-0.12	-1.31	0.19			
Disease Duration $\leq$ 2 years	0.18	2.19	0.03			
Camp Experience	0.08	0.83	0.41			
Maternal Age	0.08	0.88	0.38			
Marital Status	0.02	0.24	0.81			
Employed	-0.14	-1.60	0.11			
# Other Children in Home	0.05	0.54	0.59			
Caretaker Time	0.05	0.48	0.63			
Mother African-American	0.25	2.00	0.05			
Mother Non-White Minority	-0.18	-1.50	0.14			
Maternal Education	0.08	0.88	0.38			
Annual Household Income	0.15	1.74	0.08			
Step 2 – Illness Group				0.15	3.44	< .001
Child's Sex	-0.17	-2.20	0.03			
Child's Age	-0.05	-0.60	0.55			
Disease Duration $\leq$ 2 years	0.14	1.66	0.10			
Employed	-0.16	-2.02	0.05			
Mother African-American	0.22	1.91	0.06			
Mother Non-White Minority	-0.20	-1.75	0.08			
Annual Household Income	0.21	2.61	0.01			
Cancer on Treatment	0.21	2.11	0.04			
Epilepsy	0.10	0.88	0.38			
Kidney	0.38	3.81	< 0.01			
Asthma	0.17	1.52	0.13			
Step 3				0.16	4.13	< .001
Child's Sex	-0.18	-2.30	0.02			
Disease Duration $\leq$ 2 years	0.13	1.53	0.13			
Employed	-0.16	-2.06	0.04			
Mother African-American	0.21	1.84	0.07			
Mother Non-White Minority	-0.19	-1.70	0.09			
Annual Household Income	0.20	2.54	0.01			
Cancer on Treatment	0.19	2.20	0.03			
Kidney	0.33	4.11	< 0.01			
Asthma	0.12	1.48	0.14			



Table 8 – Continued

Predictor	B	t	p	Adj. R <sup>2</sup>	F	P
Step 4				0.14	4.67	< .001
Child's Sex	-0.16	-2.45	0.02			
Employed	-0.14	-1.79	0.08			
Mother African-American	0.07	1.83	0.07			
Mother Non-White Minority	-0.19	-1.67	0.10			
Annual Household Income	0.16	2.13	0.04			
Cancer on Treatment	0.21	2.75	0.01			
Kidney	0.29	3.88	< 0.01			
Step 5				0.12	6.43	< 0.01
Child's Sex	-0.15	-2.00	0.05			
Annual Household Income	0.13	1.68	0.10			
Cancer	0.22	2.80	0.01			
Kidney	0.30	3.85	< 0.01			
Step 6 – Final Model				0.12	8.96	< 0.01
Child's Sex	-0.18	-2.53	0.01			
Cancer	0.25	3.43	< 0.01			
Kidney	0.26	3.62	< 0.01			

Note. Higher scores indicate greater caregiving duration (greater time spent caregiving)

The following variables are coded yes = 1, no = 0

Child's Sex coded yes for females

Disease Duration  $\leq$  2 years coded yes if duration was less than or equal to 2 years

Marital Status coded yes if married

Employed coded yes if currently employed

African-American coded yes if African-American

Non-White Minority coded yes if non-white minority (e.g., Hispanic, Asian)

Cancer on Treatment coded yes for child with cancer on treatment

Epilepsy coded yes for child with epilepsy

Kidney coded yes for child with kidney disorder

Asthma coded yes for child with asthma

Camp Experience coded for number of previous years attended BCGC

Caretaker Time coded in percent of time mother considers herself primary caretaker

Table 9: Hierarchical Multiple Regression Steps: Predictors of Subjective Stress

Predictor	B	t	p	Adj. R <sup>2</sup>	F	p
Step 1 – Demographics				0.03	1.32	0.21
Child's Sex	-0.12	-1.38	0.17			
Child's Age	-0.09	-0.94	0.35			
Disease Duration $\leq 2$ years	0.07	0.86	0.39			
Camp Experience	-0.07	-0.82	0.42			
Maternal Age	0.12	1.24	0.22			
Marital Status	0.02	0.19	0.85			
Employed	0.08	0.89	0.38			
# Other Children in Home	0.13	1.50	0.14			
Caretaker Time	0.08	0.78	0.44			
Mother African-American	0.24	1.86	0.07			
Mother Non-White Minority	-0.08	-0.63	0.53			
Maternal Education	-0.04	-0.49	0.63			
Annual Household Income	0.00	-0.03	0.98			
Step 2 – Illness Group				0.09	3.21	< 0.01
Child's Sex	-0.13	-1.78	0.08			
Maternal Age	0.07	0.90	0.37			
# Other Children in Home	0.08	1.12	0.26			
Mother African-American	0.16	2.20	0.03			
Cancer on Treatment	0.21	2.25	0.03			
Epilepsy	-0.05	-0.53	0.60			
Kidney	0.16	1.67	0.10			
Asthma	0.13	1.29	0.20			
Step 3				0.10	4.15	< 0.01
Child's Sex	-0.12	-1.71	0.09			
# Other Children in Home	0.07	0.98	0.33			
Mother African-American	0.16	2.17	0.03			
Cancer on Treatment	0.22	2.84	0.01			
Kidney	0.19	2.43	0.02			
Asthma	0.17	2.11	0.04			
Step 4 – Objective Stress				0.25	9.48	< 0.01
Child's Sex	-0.04	-0.60	0.55			
Mother African-American	0.15	2.23	0.03			
Cancer on Treatment	0.15	2.06	0.04			
Kidney	0.05	0.66	0.51			
Asthma	0.15	2.05	0.04			
Caregiving Frequency	0.33	4.27	< 0.01			
Caregiving Duration	0.16	2.00	0.05			

Table 9 – Continued

Predictor	B	t	p	Adj. R <sup>2</sup>	F	p
Step 5 – Final Model				0.26	13.22	< 0.01
Mother African-American	0.15	2.34	0.02			
Cancer on Treatment	0.13	1.97	0.05			
Asthma	0.14	2.02	0.05			
Caregiving Frequency	0.34	4.55	< 0.01			
Caregiving Duration	0.17	2.20	0.03			

Note. Higher scores indicate greater caregiving stress

The following variables are coded yes = 1, no = 0

Child's Sex coded yes for females

Disease Duration  $\leq$  2 years coded yes if duration was less than or equal to 2 years

Marital Status coded yes if married

Employed coded yes if currently employed

African-American coded yes if African-American

Non-White Minority coded yes if non-white minority (e.g., Hispanic, Asian)

Cancer on Treatment coded yes for child with cancer on treatment

Epilepsy coded yes for child with epilepsy

Kidney coded yes for child with kidney disorder

Asthma coded yes for child with asthma

Camp Experience coded for number of previous years attended BCGC

Caretaker Time coded in percent of time mother considers herself primary caretaker

Table 10: Hierarchical Multiple Regression Steps: Predictors of Overload

Predictor	B	t	p	Adj. R <sup>2</sup>	F	p
Step 1 - Demographics				-0.01	0.83	0.62
Child's Sex	-0.13	-1.49	0.14			
Child's Age	0.05	0.54	0.59			
Disease Duration $\leq$ 2 years	-0.05	-0.56	0.58			
Camp Experience	-0.06	-0.65	0.52			
Maternal Age	-0.03	-0.35	0.73			
Marital Status	0.07	0.66	0.51			
Employed	-0.01	-0.13	0.90			
# Other Children in Home	0.02	0.24	0.81			
Caretaker Time	0.22	2.17	0.03			
Mother African-American	0.07	0.51	0.61			
Mother Non-White Minority	-0.03	-0.25	0.81			
Maternal Education	-0.03	-0.38	0.70			
Annual Household Income	-0.04	-0.41	0.69			
Step 2 - Illness Group				0.04	2.22	0.04
Child's Sex	-0.13	-1.69	0.09			
Caretaker Time	0.17	2.25	0.03			
Cancer on Treatment	0.18	1.92	0.06			
Epilepsy	0.07	0.66	0.51			
Kidney	0.04	0.46	0.65			
Asthma	0.02	0.14	0.89			
Step 3 - Objective Stress				0.05	2.88	0.02
Child's Sex	-0.11	-1.39	0.17			
Caretaker Time	0.17	2.24	0.03			
Cancer on Treatment	0.14	1.83	0.07			
Caregiving Frequency	0.05	0.55	0.58			
Caregiving Duration	0.06	0.71	0.48			
Step 4 - Subjective Stress				0.10	6.12	< 0.01
Child's Sex	-0.09	-1.21	0.23			
Caretaker Time	0.15	2.10	0.04			
Cancer on Treatment	0.12	1.67	0.10			
Caregiving Stress	0.24	3.30	< 0.01			
Step 5				0.10	7.65	< 0.01
Caretaker Time	0.14	1.97	0.05			
Cancer on Treatment	0.12	1.66	0.10			
Caregiving Stress	0.25	3.51	< 0.01			
Step 6 - Final Subjective Stress Model				0.09	10.00	< 0.01
Caretaker Time	0.15	2.13	0.03			
Caregiving Stress	0.27	3.75	< 0.01			

Note. Higher scores indicate greater overload scores

Table 10 – Continued

The following variables are coded yes = 1, no = 0

Child's Sex coded yes for females

Disease Duration  $\leq 2$  years coded yes if duration was less than or equal to 2 years

Marital Status coded yes if married

Employed coded yes if currently employed

African-American coded yes if African-American

Non-White Minority coded yes if non-white minority (e.g., Hispanic, Asian)

Cancer on Treatment coded yes for child with cancer on treatment

Epilepsy coded yes for child with epilepsy

Kidney coded yes for child with kidney disorder

Asthma coded yes for child with asthma

Camp Experience coded for number of previous years attended BCGC

Caretaker Time coded in percent of time mother considers herself primary caretaker

Table 11: Hierarchical Multiple Regression Steps: Predictors of Depression-Anxiety

Predictor	B	t	p	Adj. R <sup>2</sup>	F	p
Step 1 - Demographics				0.04	1.47	0.14
Child's Sex	-0.03	-0.41	0.68			
Child's Age	0.09	0.98	0.33			
Disease Duration $\leq$ 2 years	-0.02	-0.20	0.84			
Camp Experience	0.09	0.99	0.33			
Maternal Age	-0.05	-0.58	0.56			
Marital Status	0.07	0.74	0.46			
Employed	-0.16	-1.74	0.08			
# Other Children in Home	-0.05	-0.61	0.55			
Caretaker Time	0.16	1.59	0.11			
Mother African-American	0.19	1.53	0.13			
Mother Non-White Minority	0.06	0.48	0.63			
Maternal Education	0.11	1.21	0.23			
Annual Household Income	0.04	0.46	0.65			
Step 2 - Illness Group				0.07	2.68	0.01
Employed	-0.15	-1.85	0.07			
Caretaker Time	0.07	0.83	0.41			
Mother African-American	0.19	2.43	0.02			
Maternal Education	0.09	1.24	0.22			
Cancer on Treatment	0.12	1.31	0.19			
Epilepsy	0.05	0.45	0.66			
Kidney	0.10	1.01	0.31			
Asthma	-0.11	-1.04	0.30			
Step 3 - Objective Stress				0.08	3.07	0.01
Employed	-0.15	-1.96	0.05			
Mother African-American	0.20	2.75	0.01			
Maternal Education	0.08	1.00	0.32			
Cancer on Treatment	0.07	0.91	0.37			
Asthma	-0.16	-2.15	0.03			
Caregiving Frequency	0.01	0.12	0.91			
Caregiving Duration	0.09	1.03	0.30			
Step 4				0.08	4.97	< 0.01
Employed	-0.14	-1.85	0.07			
Mother African-American	0.19	2.57	0.01			
Asthma	-0.18	-2.45	0.02			
Caregiving Duration	0.12	1.65	0.10			

Table 11 – Continued

Predictor	B	t	p	Adj. R <sup>2</sup>	F	p
Step 5 – Subjective Stress				0.11	5.50	< 0.01
Employed	-0.15	-2.05	0.04			
Mother African-American	-0.16	2.16	0.03			
Cancer on Treatment	-0.19	-2.62	0.01			
Asthma	0.05	0.61	0.54			
Caregiving Stress	0.21	2.89	< 0.01			
Step 6 – Final Subjective Stress Model				0.12	6.80	< 0.01
Employed	-0.15	-2.12	0.04			
Mother African-American	0.15	2.12	0.04			
Asthma	-0.20	-2.86	0.01			
Caregiving Stress	0.22	3.06	< 0.01			

Note. Higher scores indicate greater depression-anxiety score

The following variables are coded yes = 1, no = 0

Child's Sex coded yes for females

Disease Duration  $\leq 2$  years coded yes if duration was less than or equal to 2 years

Marital Status coded yes if married

Employed coded yes if currently employed

African-American coded yes if African-American

Non-White Minority coded yes if non-white minority (e.g., Hispanic, Asian)

Cancer on Treatment coded yes for child with cancer on treatment

Epilepsy coded yes for child with epilepsy

Kidney coded yes for child with kidney disorder

Asthma coded yes for child with asthma

Camp Experience coded for number of previous years attended BCGC

Caretaker Time coded in percent of time mother considers herself primary caretaker



Table 12: Hierarchical Multiple Regression Steps: Predictors of Maternal Distress

Predictor	B	t	p	Adj. R <sup>2</sup>	F	p
Step 1 - Demographics				0.01	1.12	0.35
Child's Sex	-0.01	-0.16	0.87			
Child's Age	0.16	1.70	0.09			
Disease Duration $\leq$ 2 years	0.03	0.39	0.70			
Camp Experience	0.06	0.69	0.49			
Maternal Age	-0.03	0.34	0.73			
Marital Status	0.04	0.42	0.68			
Employed	-0.12	-1.31	0.19			
# Other Children in Home	-0.01	-0.08	0.93			
Caretaker Time	0.07	0.69	0.49			
Mother African-American	0.24	1.86	0.07			
Mother Non-White Minority	-0.04	-0.28	0.78			
Maternal Education	-0.03	-0.36	0.72			
Annual Household Income	0.04	0.41	0.68			
Step 2 - Illness Group				0.08	3.12	< 0.01
Child's Age	0.12	1.47	0.14			
Employed	-0.13	-1.74	0.08			
Mother African-American	0.20	2.71	0.01			
Cancer on Treatment	0.05	0.54	0.59			
Epilepsy	-0.12	-1.09	0.28			
Kidney	-0.13	-1.39	0.17			
Asthma	-0.24	-2.31	0.02			
Step 3 - Objective Stress				0.08	2.95	< 0.01
Child's Age	0.13	1.55	0.12			
Employed	-0.13	-1.79	0.08			
Mother African-American	-0.19	-2.13	0.03			
Epilepsy	-0.17	-1.73	0.09			
Kidney	-0.19	-2.13	0.03			
Asthma	-0.28	-3.21	< 0.01			
Caregiving Frequency	0.11	1.28	0.20			
Caregiving Duration	-0.01	-0.16	0.87			
Step 4				0.09	3.39	< 0.01
Child's Age	0.13	1.55	0.12			
Employed	-0.13	-1.79	0.08			
Mother African-American	0.19	2.63	0.01			
Epilepsy	-0.17	-1.75	0.08			
Kidney	-0.19	-2.14	0.03			
Asthma	-0.28	-3.23	< 0.01			
Caregiving Frequency	0.11	1.40	0.16			

Table 12 – Continued

Predictor	B	t	p	Adj. R <sup>2</sup>	F	p
Step 5 – Subjective Stress				0.17	6.33	< 0.01
Child's Age	0.13	1.60	0.10			
Employed	-0.13	-1.83	0.07			
Mother African-American	0.14	2.04	0.04			
Epilepsy	-0.08	-0.90	0.28			
Kidney	-0.16	-1.89	0.03			
Asthma	-0.28	-3.31	< 0.01			
Caregiving Stress	0.34	4.29	< 0.01			
Step 6				0.17	7.18	< 0.01
Child's Age	0.10	1.37	0.17			
Employed	-0.13	-1.85	0.07			
Mother African-American	0.15	2.06	0.04			
Kidney	-0.14	-1.90	0.06			
Asthma	-0.24	-3.25	< 0.01			
Caregiving Stress	0.33	4.65	< 0.01			
Step 7				0.17	8.19	< 0.01
Employed	-0.12	-1.75	0.08			
Mother African-American	0.15	2.13	0.03			
Kidney	-0.13	-1.79	0.08			
Asthma	-0.27	-3.70	< 0.01			
Caregiving Stress	0.32	4.52	< 0.01			
Step 8				0.15	11.10	< 0.01
Mother African-American	0.13	1.80	0.07			
Asthma	-0.24	-3.42	< 0.01			
Caregiving Stress	0.30	4.28	< 0.01			
Step 9 – Final Subjective Stress Model				0.14	14.84	< 0.01
Asthma	-0.23	-3.28	< 0.01			
Caregiving Stress	0.33	4.66	< 0.01			

Note. Higher scores indicate greater maternal distress score

The following variables are coded yes = 1, no = 0

Child's Sex coded yes for females

Disease Duration ≤ 2 years coded yes if duration was less than or equal to 2 years

Marital Status coded yes if married

Employed coded yes if currently employed

African-American coded yes if African-American

Non-White Minority coded yes if non-white minority (e.g., Hispanic, Asian)

Cancer on Treatment coded yes for child with cancer on treatment

Epilepsy coded yes for child with epilepsy

Kidney coded yes for child with kidney disorder

Asthma coded yes for child with asthma

Camp Experience coded for number of previous years attended BCGC

Caretaker Time coded in percent of time mother considers herself primary caretaker

Table 13: Hierarchical Multiple Regression Steps: Predictors of Recreational Activities

Predictor	B	T	p	Adj. R <sup>2</sup>	F	P
Step 1 – Demographics				< 0.01	1.04	0.42
Child's Sex	-0.05	-0.54	0.59			
Child's Age	0.03	0.36	0.72			
Disease Duration ≤ 2 years	-0.13	-1.56	0.12			
Camp Experience	-0.13	-1.35	0.18			
Maternal Age	0.02	0.25	0.81			
Marital Status	-0.10	-0.98	0.33			
Employed	-0.21	-2.35	0.02			
# Other Children in Home	-0.02	-0.27	0.79			
Caretaker Time	-0.07	-0.74	0.46			
Mother African-American	-0.05	-0.39	0.70			
Mother Non-White Minority	-0.07	-0.56	0.58			
Maternal Education	0.09	1.04	0.30			
Annual Household Income	0.03	0.32	0.75			
Step 2 – Illness Group				0.04	2.03	0.05
Disease Duration ≤ 2 years	-0.01	-0.15	0.89			
Camp Experience	-0.06	-0.68	0.50			
Employed	-0.16	-2.07	0.04			
Cancer on Treatment	-0.05	-0.53	0.60			
Epilepsy	0.12	1.12	0.27			
Kidney	0.02	0.21	0.84			
Asthma	0.22	1.98	0.05			
Step 3 – Objective Stress				0.07	3.50	0.01
Employed	-0.14	-1.89	0.06			
Epilepsy	0.15	1.81	0.07			
Asthma	0.26	3.21	< 0.01			
Caregiving Frequency	-0.17	-1.95	0.05			
Caregiving Duration	0.07	0.79	0.43			
Step 4				0.07	4.23	< 0.01
Employed	-0.15	-2.07	0.04			
Epilepsy	0.13	1.66	0.10			
Asthma	0.25	3.13	< 0.01			
Caregiving Frequency	-0.13	-1.81	0.07			
Step 5 - Final Objective Stress Model				0.06	4.68	< 0.01
Employed	-0.15	-2.07	0.04			
Asthma	0.20	2.69	0.01			
Caregiving Frequency	-0.13	-1.78	0.08			

Table 13 – Continued

Predictor	B	t	p	Adj. R <sup>2</sup>	F	P
Step 6 – Subjective Stress				0.07	4.12	< 0.01
Employed	-0.15	-2.11	0.04			
Epilepsy	0.10	1.28	0.20			
Asthma	0.25	3.16	< 0.01			
Caregiving Stress	-0.13	-1.69	0.09			
Step 7 – Final Subjective Stress Model				0.06	4.92	< 0.01
Employed	-0.15	-2.11	0.04			
Asthma	0.21	2.88	< 0.01			
Caregiving Stress	-0.14	-1.97	0.05			
Step 8 – Mediator Model				0.06	3.95	< 0.01
Employed	-0.15	-2.08	0.04			
Asthma	0.21	2.83	0.01			
Caregiving Frequency	-0.08	-1.01	0.32			
Caregiving Stress	-0.11	-1.31	0.19			

Note. Higher scores indicate greater time spent in recreational activities

The following variables are coded yes = 1, no = 0

Child's Sex coded yes for females

Disease Duration  $\leq 2$  years coded yes if duration was less than or equal to 2 years

Marital Status coded yes if married

Employed coded yes if currently employed

African-American coded yes if African-American

Non-White Minority coded yes if non-white minority (e.g., Hispanic, Asian)

Cancer on Treatment coded yes for child with cancer on treatment

Epilepsy coded yes for child with epilepsy

Kidney coded yes for child with kidney disorder

Asthma coded yes for child with asthma

Camp Experience coded for number of previous years attended BCGC

Caretaker Time coded in percent of time mother considers herself primary caretaker

Table 14: ANOVA Summary Tables

Source	df	MS	F	p
CAREGIVING FREQUENCY				
Between Subjects				
Group	4	3363.59	9.27	0.00
Error	156	362.98		
Within Subjects				
Time	2	249.98	2.37	0.10
Time x Illness Group	8	235.65	2.24	0.03
Error (Time)	312	105.36		
CAREGIVING DURATION				
Between Subjects				
Group	4	19069.83	7.43	< 0.01
Error	156	2567.88		
Within Subjects				
Time	2	1065.98	0.94	0.39
Time x Illness Group	8	868.69	0.76	0.63
Error (Time)	312	1136.42		
CAREGIVING STRESS				
Between Subjects				
Group	4	1975.84	4.08	< 0.01
Error	156	484.16		
Within Subjects				
Time	2	164.93	0.84	0.43
Time x Illness Group	8	225.72	1.15	0.33
Error (Time)	312	196.38		
MATERNAL OVERLOAD				
Between Subjects				
Group	4	13.85	0.49	0.75
Error	138	28.57		
Within Subjects				
Time	3	100.36	24.61	< 0.01
Time x Illness Group	12	7.67	1.88	0.04
Error (Time)	414			

Table 14 – Continued

Source	df	MS	F	p
DEPRESSION-ANXIETY				
	Between Subjects			
Group	4	1.96	0.27	0.90
Error	138	7.38		
	Within Subjects			
Time	3	6.18	4.95	< 0.01
Time x Illness Group	12	1.48	1.18	0.29
Error (Time)	414	1.25		
MATERNAL DISTRESS				
	Between Subjects			
Group	4	30.11	0.45	0.78
Error	138	67.56		
	Within Subjects			
Time	3	84.64	9.90	< 0.01
Time x Illness Group	12	26.69	3.12	< 0.01
Error (Time)	414	8.55		
RECREATIONAL ACTIVITIES				
	Between Subjects			
Group	4	692.67	0.59	0.67
Error	138	1169.42		
	Within Subjects			
Time	3	283.99	0.63	0.60
Time x Illness Group	12	806.19	1.77	0.05
Error (Time)	414			

Table 15: Adjusted Means and Standard Deviations for ANOVAs

Variable Illness Group	<u>Pre-Camp</u> M (SD)	<u>One week</u> <u>Post-Camp</u> M (SD)	<u>One month</u> <u>Post-Camp</u> M (SD)	<u>Collapsed</u> <u>Across Time</u> M (SD)
Caregiving Frequency				
Cancer on Treatment	18.45 (11.86)	16.15 (14.11)	14.40 (15.78)	16.33 (10.03)
Epilepsy	15.76 (10.52)	12.85 (7.84)	12.59 (10.55)	13.73 (7.66)
Kidney	28.36 (25.43)	24.05 (18.87)	19.59 (19.36)	24.00 (17.34)
Asthma	15.94 (12.26)	18.75 (13.58)	20.62 (13.58)	18.44 (11.76)
Cancer Not on Treatment	5.68 (8.26)	7.88 (11.25)	4.00 (7.12)	5.85 (7.93)
Caregiving Duration				
Cancer on Treatment	5.61 (4.58)	7.24 (8.00)	6.51 (9.20)	6.45 (5.77) <sup>abc</sup>
Epilepsy	1.80 (3.43)	2.52 (5.89)	1.87 (3.89)	2.06 (3.21) <sup>ad</sup>
Kidney	6.67 (7.54)	5.08 (5.22)	4.32 (5.10)	5.36 (4.12) <sup>d</sup>
Asthma	2.76 (3.58)	2.64 (4.26)	2.89 (5.48)	2.76 (3.19) <sup>b</sup>
Cancer Not on Treatment	1.79 (3.61)	2.81 (6.41)	1.14 (2.17)	1.91 (3.51) <sup>cd</sup>
Caregiving Stress				
Cancer on Treatment	15.45 (20.60)	6.80 (12.45)	8.45 (15.15)	10.23 (11.15)
Epilepsy	3.50 (7.69)	5.09 (9.05)	5.20 (10.24)	4.59 (7.43) <sup>ab</sup>
Kidney	15.68 (24.27)	17.27 (28.27)	9.09 (13.96)	14.02 (15.72) <sup>a</sup>
Asthma	11.60 (17.17)	12.19 (20.88)	13.06 (25.18)	12.28 (16.46) <sup>b</sup>
Cancer Not on Treatment	4.52 (11.04)	2.92 (9.32)	4.28 (17.18)	3.91 (10.02)

Note. Means sharing superscripts within each variables were significantly on post-hoc analysis using Tukey's HSD.



Table 15 -- Continued

Variable	<u>Pre-Camp</u>	<u>One week</u>	<u>One month</u>	<u>Collapsed</u>
Illness Group	<u>M (SD)</u>	<u>Post-Camp</u>	<u>Post-Camp</u>	<u>Across Time</u>
	<u>M (SD)</u>	<u>M (SD)</u>	<u>M (SD)</u>	<u>M (SD)</u>
Overload				
Cancer on Treatment	11.33 (3.03)	8.33 (3.11)	9.22 (2.98)	8.61 (3.26)
Epilepsy	10.09 (3.12)	7.95 (2.97)	9.23 (3.83)	9.26 (9.87)
Kidney	10.00 (2.97)	7.29 (2.86)	10.17 (3.28)	9.61 (3.05)
Asthma	9.91 (3.10)	7.96 (2.57)	9.69 (2.97)	9.24 (3.05)
Cancer Not on Treatment	10.06 (3.20)	8.18 (3.47)	8.05 (3.23)	7.95 (2.59)
Depression-Anxiety				
Cancer on Treatment	2.44 (1.69)	1.83 (1.50)	2.17 (1.86)	1.94 (1.95)
Epilepsy	2.09 (1.70)	1.58 (1.59)	1.95 (1.88)	1.74 (1.63)
Kidney	2.50 (1.72)	1.33 (1.46)	2.11 (1.94)	1.89 (1.91)
Asthma	1.64 (1.39)	1.60 (1.25)	1.83 (1.83)	1.83 (1.68)
Cancer Not on Treatment	2.18 (1.44)	1.77 (1.74)	1.41 (1.47)	2.00 (1.88)
Maternal Distress				
Cancer on Treatment	17.11 (5.52)	15.61 (4.45)	15.61 (4.46)	15.11 (5.50)
Epilepsy	16.23 (4.21)	14.67 (4.99)	15.78 (5.22)	13.72 (4.55)
Kidney	16.11 (4.89)	13.61 (4.90)	16.66 (5.36)	16.28 (5.92)
Asthma	14.52 (4.30)	14.61 (4.50)	14.64 (4.54)	14.52 (4.78)
Cancer Not on Treatment	17.64 (4.65)	14.18 (5.46)	13.85 (4.89)	13.36 (4.88)
Recreational Activity Time				
Cancer on Treatment	25.75 (16.27)	29.48 (12.73)	32.30 (25.89)	30.94 (21.23)
Epilepsy	39.29 (28.05)	30.30 (18.81)	28.54 (21.84)	32.52 (25.50)
Kidney	29.11 (16.53)	40.95 (33.84)	23.76 (17.21)	33.27 (21.95)
Asthma	44.48 (34.31)	34.00 (27.32)	31.24 (33.75)	29.78 (25.13)
Cancer Not on Treatment	28.35 (19.05)	25.98 (14.72)	34.43 (29.91)	26.65 (13.91)

Note. Cancer on Treatment (n = 20), Epilepsy (n = 46), Kidney (n = 22), Asthma (n = 48),  
Cancer Not on Treatment (n = 25)

Table 16: Comparison of Means for Overload Using Paired t-tests

	Mean	SD	df	$\bar{T}$
Pre-camp	10.05	3.14	152	9.13*
During-camp	7.98	2.88		
Pre-camp	10.05	3.14	155	3.66*
One week post camp	9.25	3.30		
Pre-camp	10.05	3.14	149	4.35*
One month post-camp	8.98	3.26		
During camp	7.98	2.88	149	-5.35*
One week post-camp	9.25	3.30		
One week post-camp	9.25	3.30	149	1.45
One month post-camp	8.98	3.26		

\*Significant by Bonferroni adjusted  $p < .05$

Table 17: Comparison of Means for Depression-Anxiety Using Paired t-tests

	Mean	SD	Df	t
Pre-camp	2.09	1.58	152	3.45*
During-camp	1.63	1.52		
Pre-camp	2.06	1.58	155	1.25
One week post camp	1.89	1.79		
Pre-camp	2.05	1.57	149	1.41
One month post-camp	1.86	1.76		
During camp	1.63	1.52	149	-2.10
One week post-camp	1.90	1.79		
One week post-camp	1.64	1.48	144	-1.68
One month post-camp	1.85	1.73		

\*Significant by Bonferroni adjusted  $p < .05$

Table 18: MANOVA Summary Tables

Source	df	F	p
<u>Cancer on Treatment</u>			
Time (T)	2, 18	1.77	0.20
Caregiver Burden Measures (C)	2, 18	0.15	0.86
T x C	4, 16	1.09	0.40
Time (T)	3, 15	3.83	0.03
Outcome Measures (O)	3, 15	4.58	0.02
T x O	9, 9	2.10	0.14
<u>Epilepsy</u>			
Time (T)	2, 44	3.07	0.05
Caregiver Burden Measures (C)	2, 44	0.12	0.89
T x C	4, 42	2.25	0.08
Time (T)	3, 40	0.85	0.48
Outcome Measures (O)	3, 40	8.12	<.01
T x O	9, 34	1.41	0.22
<u>Kidney</u>			
Time (T)	2, 20	0.43	0.66
Caregiver Burden Measures (C)	2, 20	1.61	0.23
T x C	4, 18	0.38	0.82
Time (T)	3, 15	1.60	0.23
Outcome Measures (O)	3, 15	1.37	0.29
T x O	9, 9	1.66	0.23
<u>Asthma</u>			
Time (T)	2, 46	1.69	0.20
Caregiver Burden Measures (C)	2, 46	0.46	0.64
T x C	4, 44	0.98	0.43
Time (T)	3, 39	1.86	0.15
Outcome Measures (O)	3, 39	2.33	0.09
T x O	9, 33	2.29	0.04

Table 18 – Continued

Source	df	F	p
<u>Cancer Not on Treatment</u>			
Time (T)	2, 23	0.20	0.82
Caregiver Burden Measures (C)	2, 23	0.65	0.53
T x C	4, 21	0.81	0.53
Time (T)	3, 19	3.81	0.03
Outcome Measures (O)	3, 19	3.68	0.03
T x O	9, 13	2.53	0.06

Table 19: Means and Standard Deviations for MANOVAs

Illness Group Variable	Pre-Camp M (SD)	During Camp <sup>a</sup> M (SD)	One week Post-Camp M (SD)	One month Post-Camp M (SD)
Cancer on Treatment				
Caregiving Frequency	0.00 (1.00)		-0.19 (1.19)	-0.34 (1.33)
Caregiving Duration	0.00 (1.00)		0.36 (1.75)	0.20 (2.01)
Caregiving Stress	0.00 (1.00)		-0.42 (0.60)	-0.34 (0.74)
Overload	0.01 (1.00)	-0.98 (1.03)	-0.69 (0.98)	-0.89 (1.07)
Depression-Anxiety	0.00 (1.00)	-0.38 (0.94)	-0.18 (1.15)	-.31 (1.21)
Maternal Distress	0.00 (1.00)	-0.27 (0.85)	-0.27 (0.85)	-0.37 (1.05)
Recreational Activities	0.00 (1.00)	0.27 (0.83)	0.45 (1.68)	0.36 (1.38)
Epilepsy				
Caregiving Frequency	0.00 (1.00)		-0.28 (0.75)	-0.30 (1.00)
Caregiving Duration	0.00 (1.00)		0.21 (1.72)	0.01 (1.13)
Caregiving Stress	0.00 (1.00)		0.21 (1.18)	0.22 (1.33)
Overload	0.00 (1.00)	-0.72 (0.98)	-0.29 (1.26)	-0.28 (1.27)
Depression-Anxiety	0.00 (1.00)	-0.34 (0.96)	-0.12 (1.13)	-0.24 (0.98)
Maternal Distress	0.00 (1.00)	-0.39 (1.15)	-0.13 (1.20)	-0.61 (1.05)
Recreational Activities	0.00 (1.00)	-0.29 (.68)	-0.35 (.79)	-0.21 (0.93)
Kidney				
Caregiving Frequency	0.00 (1.00)		-0.17 (0.74)	-0.34 (0.76)
Caregiving Duration	0.00 (1.00)		-0.21 (0.69)	-0.31 (0.68)
Caregiving Stress	0.00 (1.00)		-0.06 (1.16)	-0.27 (0.58)
Overload	0.03 (1.05)	-0.92 (1.01)	0.09 (1.16)	-0.11 (1.08)
Depression-Anxiety	0.00 (0.96)	-0.65 (.81)	-0.22 (1.08)	-0.34 (1.07)
Maternal Distress	0.05 (0.97)	-0.56 (0.97)	0.05 (1.07)	-0.03 (1.18)
Recreational Activities	0.04 (1.06)	0.80 (2.17)	-0.30 (1.10)	0.31 (1.41)
Asthma				
Caregiving Frequency	0.00 (1.00)		0.22 (1.11)	0.38 (1.42)
Caregiving Duration	0.00 (1.00)		-0.03 (1.19)	0.38 (1.53)
Caregiving Stress	0.00 (1.00)		0.03 (1.22)	0.09 (1.47)
Overload	0.02 (1.00)	-0.60 (0.82)	-0.05 (0.95)	-0.19 (0.97)
Depression-Anxiety	0.00 (1.00)	-0.03 (0.91)	0.14 (1.34)	0.14 (1.23)
Maternal Distress	0.00 (1.00)	0.01 (1.05)	0.01 (1.06)	-0.02 (1.12)
Recreational Activities	0.00 (1.00)	-0.31 (0.81)	-0.37 (1.01)	-0.45 (0.73)

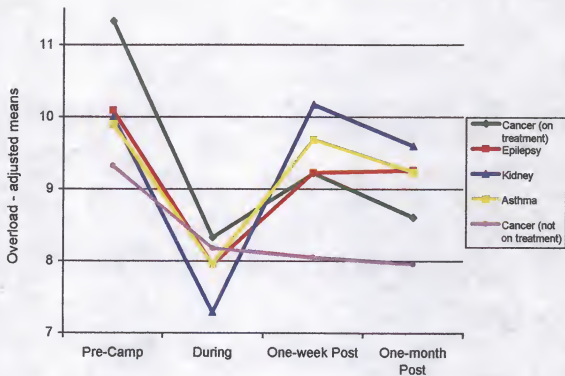
Table 19 – Continued

Illness Group Variable	<u>Pre-Camp</u>	<u>During Camp<sup>a</sup></u>	<u>One week</u> <u>Post-Camp</u>	<u>One month</u> <u>Post-Camp</u>
	M (SD)	M (SD)	M (SD)	M (SD)
Cancer Not on Treatment				
Caregiving Frequency	0.00 (1.00)		0.27 (1.36)	-0.20 (0.86)
Caregiving Duration	0.00 (1.00)		0.28 (1.78)	-0.18 (0.60)
Caregiving Stress	0.00 (1.00)		-0.14 (0.84)	-0.02 (1.56)
Overload	0.03 (1.01)	-0.35 (0.96)	-0.39 (0.89)	-0.41 (0.72)
Depression-Anxiety	0.09 (1.00)	-0.19 (1.22)	-0.44 (1.03)	-0.03 (1.31)
Maternal Distress	0.07 (1.05)	-0.71 (1.23)	-0.78 (1.10)	-0.89 (1.10)
Recreational Activities	0.07 (1.01)	-0.19 (0.78)	0.26 (1.58)	-0.16 (0.74)

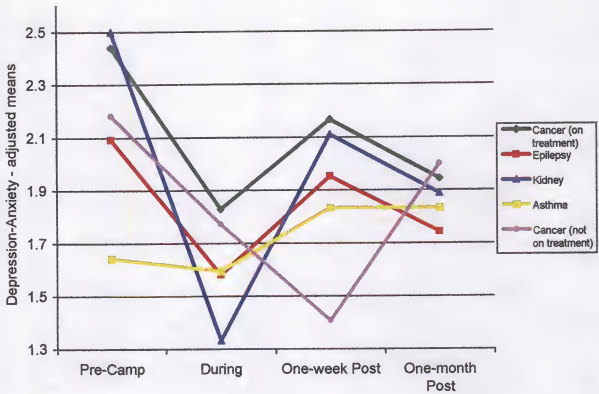
Note. Cancer on Treatment (n = 20), Epilepsy (n = 46), Kidney (n = 22), Asthma (n = 48),  
Cancer Not on Treatment (n = 25)

<sup>a</sup>Caregiving Frequency, Duration and Stress not assessed at the During Camp interview

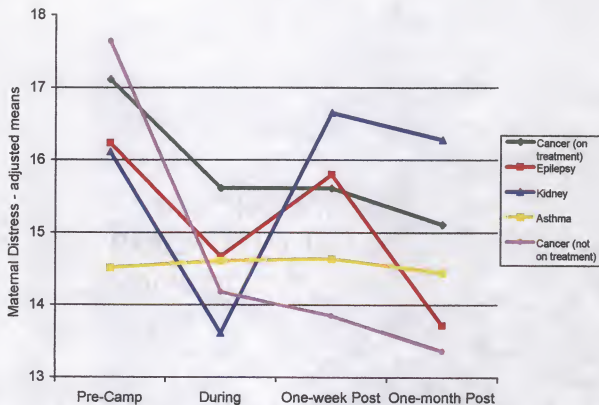




**Figure 2.** Average rating of overload for previous week



**Figure 3.** Average rating of depression-anxiety for previous week



**Figure 4.** Average rating of maternal distress for previous week

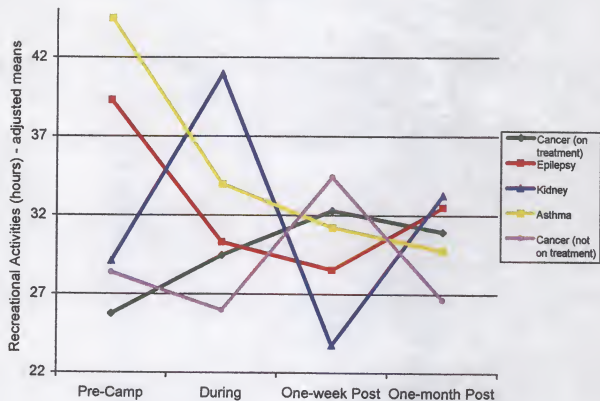
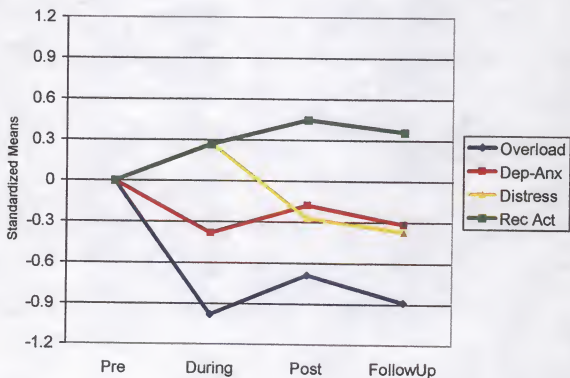
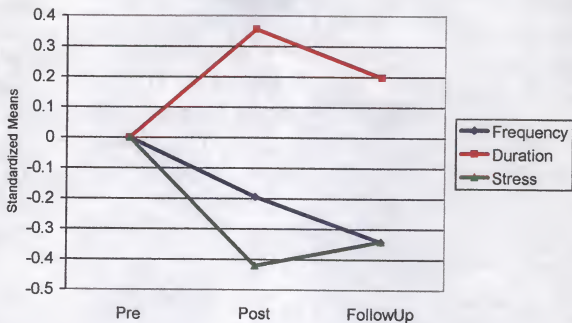
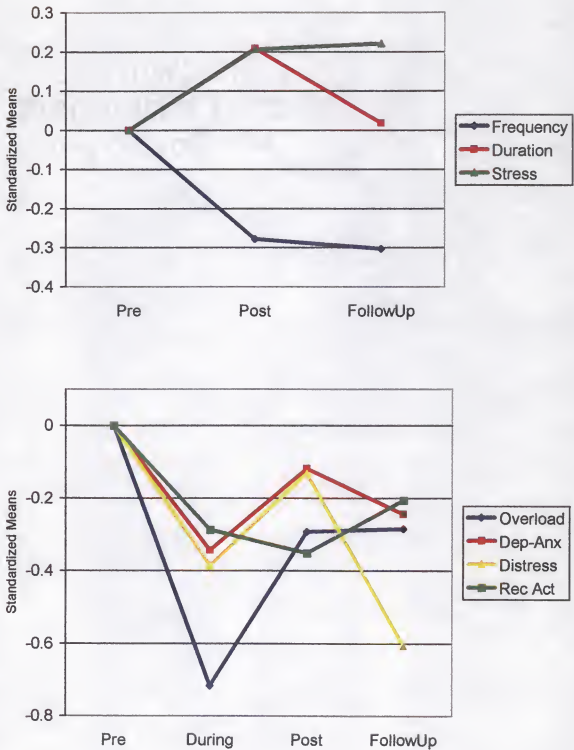


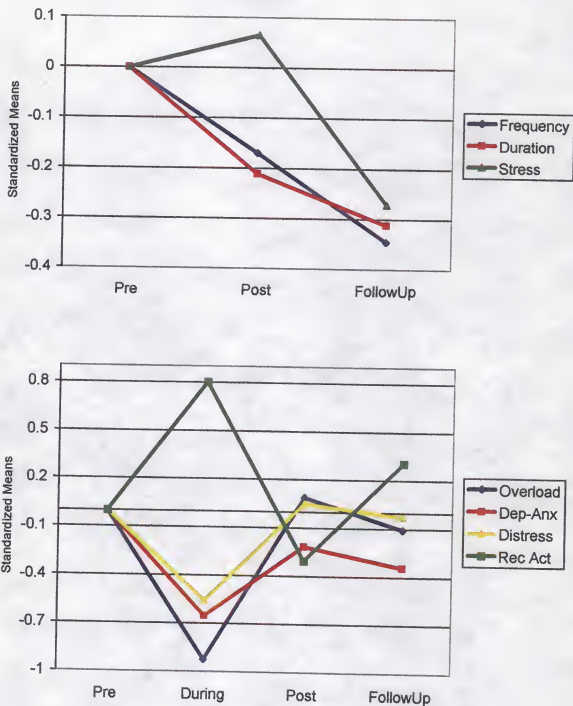
Figure 5. Average time spent in recreational activities during the previous week



**Figure 6.** Comparison of Objective Stress, Subjective Stress, and Outcomes for Cancer on Treatment



**Figure 7.** Comparison of Objective Stress, Subjective Stress, and Outcomes for Epilepsy



**Figure 8.** Comparison of Objective Stress, Subjective Stress, and Outcomes for Kidney



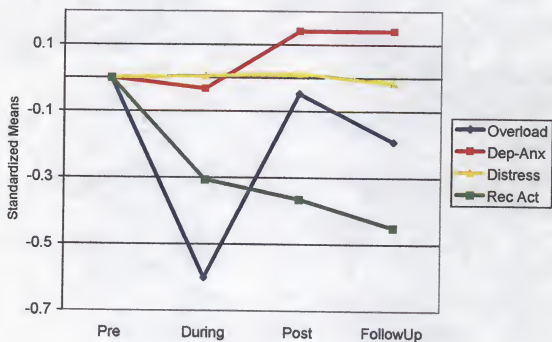
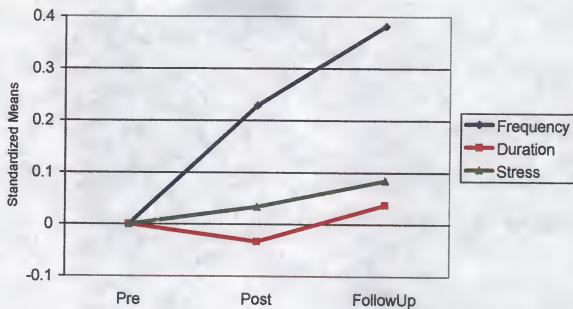
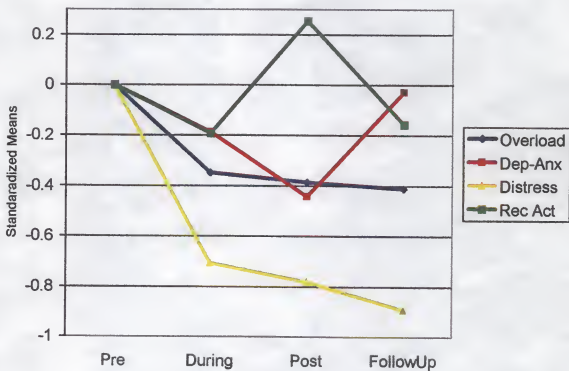
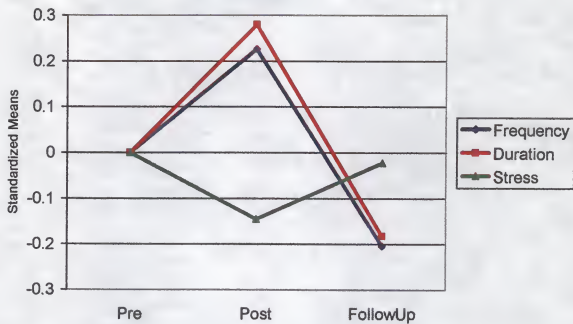


Figure 9. Comparison of Objective Stress, Subjective Stress, and Outcomes for Asthma



**Figure 10.** Comparison of Objective Stress, Subjective Stress, and Outcomes for Cancer Not on Treatment

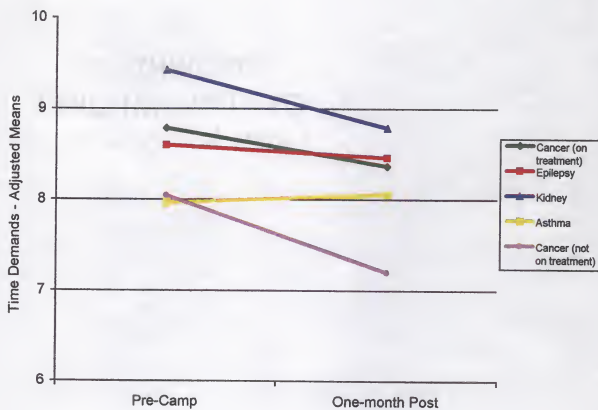


Figure 11. Average rating of time demands for previous month

## DISCUSSION

This study supported the proposed model of caregiver burden, demonstrating an indirect effect of caregiving activities on psychosocial outcome variables through subjective stress. In addition, this study demonstrated illness group differences in terms of the amount of objective stress and subjective stress experienced by mothers of children with cancer (on and off treatment), epilepsy, kidney disorders, and asthma. The results from this study also indicated that summer camps for children with chronic illnesses provide respite care for mothers by improving psychosocial outcomes during the respite care (camp), with some benefits maintained for up to one month after camp ended. This section will first examine the differences between the illness groups, then discuss how the data support the proposed model of caregiver burden, and finally, examine the changes in objective stress, subjective stress, and outcomes as a result of the respite care provided by a week of summer camp.

### Demographic Differences Between Illness Groups

Significant demographic differences between the illness groups were found for the child's age, the child's duration of disease, the child's previous camp experience, and maternal age. Although only child's age was predicted to differ, these results are representative of the camp's recruitment policies and camper population for the summer of 2000.

Due to the large number of children with asthma in the state of Florida, Boggy Creek Gang Camp (BCGC) only recruits children 12 years of age and younger, compared to the other sessions, where children are accepted up to the age of 16 years. Thus the finding that children with asthma were significantly younger than the other disease groups (except cancer on treatment) was expected.

Children with cancer on treatment were younger than the other disease groups (except asthma), while all children with cancer had a significantly shorter disease duration than the other illness groups. These findings were not expected, but are also consistent with camp policy. BCGC attempts to recruit newly diagnosed campers with cancer, resulting in younger children who are on treatment, and a shorter disease duration for all cancer campers. In turn, younger children tend to have younger mothers, explaining the finding that mothers of children with cancer on treatment were younger than mothers of children with epilepsy.

Another camp recruitment policy that led to demographic differences is the effort to bring new campers each summer to BCGC, limiting the number of times a child may return to camp. However, if a session is not full, return campers are invited back. Due to the large number of children with asthma in Florida, this group is limited to two summers at BCGC. However, the epilepsy session has a smaller recruitment population, resulting in multiple return campers, some of whom were returning for their 4th or 5th summer. This explains the difference in previous camp experience between the asthma and epilepsy groups.

### Differences Between Illness Groups for Caregiver Burden Variables

Significant differences between the illness groups were found for caregiving frequency, caregiving duration, and caregiving stress. This suggests that the experience of caring for a child with a chronic illness is not universal across illness types, but rather depends on the type of the child's illness.

Mothers of children with kidney disorders performed an average of 24 caregiving activities per week, significantly more than mothers of all illness groups, except cancer on treatment. However, it is important to note the large variability within the kidney disorders group. Only 25% of these mothers, likely those who had children on dialysis, performed more than 24 caregiving activities per week. This suggests that even within the illness there is a lot of variability in terms of caregiving activities. Thus it is important to consider the child's prescribed treatment regimen when examining caregiver burden.

Cancer is another example of the heterogeneity of caregiving duties within an illness group. Mothers of children with cancer on and off treatment performed a significantly different number of caregiving activities each week. While mothers of children with cancer on treatment performed over 17 caregiving activities per week, mothers of children with cancer off treatment performed between five and six. The treatment regimen of chemotherapy and/or radiation along with medication management may lead to more caregiving burden than maintenance regimens.

While mothers of children with cancer on treatment and kidney disorders spent an average of over five hours per week in caregiving, mothers of children with epilepsy spent less than two hours per week in caregiving activities. Again, differences between illness groups demonstrate how treatment regimens may impact caregiver burden.

Illnesses that have lengthy medical appointments (e.g., chemotherapy, dialysis) require more caregiving time compared to illnesses that primarily require medication management.

Overall, the mothers in this study rated 59% of their caregiving activities to be "not at all stressful." This suggests that although mothers may have to perform multiple caregiving activities that require several hours per week, over half of these activities do not appear to cause any stress for the mothers. In addition, less than 4% of caregiving activities were rated as "extremely stressful." However, it is interesting to note that depending on the type of caregiving activity, there was a difference in the percent of caregiving activities that were perceived as stressful. While over 60% of nighttime care activities were rated as stressful (stress rating  $> 0$ ), less than 35% of medications and home care procedures were rated as stressful.

Although in general mothers in this study reported that many of their caregiving activities were not at all stressful, significant differences were found between illness groups in terms of total stress ratings per week. Mothers of children with cancer on treatment, kidney disorders, and asthma all had total stress levels of over ten for the week, while mothers of children with epilepsy and cancer not on treatment reported total stress levels under five for the week. Examining the caregiving burden variables together indicates that as caregiving frequency and duration increases, in general so does caregiving stress.

However, mothers of children with epilepsy performed significantly more caregiving activities per week ( $M = 16$ ) compared to mothers of children with cancer not on treatment ( $M = 5.5$ ), yet the epilepsy group had an overall lower caregiving stress



rating (epilepsy = 3.2, cancer no treatment = 4.6). Epilepsy is a chronic illness that when managed properly does not have a significant impact on daily life. The lower stress levels experienced by these mothers would suggest that caring for their child's epilepsy does not result in significant caregiver stress.

Similarly, mothers of children with epilepsy and asthma performed a similar number of caregiving activities during the week (epilepsy = 16, asthma = 15.8). However, mothers of children with asthma reported significantly more caregiving stress (epilepsy = 3.2, asthma = 11.4). This may reflect the difference in terms of the treatment required when a medical crisis occurs. When a seizure occurs, no medical intervention occurs, but when an asthma attack occurs, it is treated with a rescue inhaler. Although both types of medical crises may result in increased caregiver stress, we only assessed the stress related to caregiving activities (e.g., administering the rescue inhaler). Without an estimate of how stressful observing a seizure may be for a mother, we may have underestimated caregiving stress for mothers of children with epilepsy.

#### Comparison of Outcome Variables to Normative Populations

In order to better understand the impact of caregiving, it was necessary to examine how the current population compared to normative populations on measures of overload, depression-anxiety, maternal distress, and time demands.

With the exception of mothers of children with cancer on treatment, overload in the current sample was consistent with a normative population of AD caregivers (Pearlin et al., 1990). This suggests that in general, mothers in this study experience feelings of burnout and fatigue that are consistent with caregivers of AD patients. It is possible that mothers of children with cancer on treatment experienced greater feelings of overload

due to shorter disease duration or the more acute nature of cancer. AD tends to be a disease with a long period of onset, often followed by a lengthy period of time that caregiving is required. This is similar to the more chronic illnesses in this study (e.g., epilepsy, asthma). However, cancer diagnoses tend to be sudden, and the duration of caregiving required after diagnosis can be uncertain.

In general, depression-anxiety scores were significantly higher for the mothers in the current sample compared to a normative population of mothers of children without a chronic illness (Breslau et al., 1982). This finding is consistent with the literature that has demonstrated that mothers of chronically ill children report more anxiety and depression than mothers of healthy children (Fielding et al., 1985; Hodges, Kline, Barbero, & Flanery, 1985; Quittner, DiGirolamo, Michel, & Eigen, 1992; Thompson, Gustafson, Hamlett, & Spock, 1992). Only mothers of children with asthma did not report higher levels of depression-anxiety. Asthma is the most common chronic illness in childhood (Creer & Bender, 1995), which may reduce some of the stigma associated with having a child with a chronic illness. In addition, although the management of asthma may require multiple caregiving activities per day, preventative treatments are brief and easy to fit into a normal routine. This appears to lead to lower levels of psychological distress for these mothers.

Mothers in the current sample reported depression-anxiety scores consistent with a normative population of mothers of children with myelodysplasia (Breslau et al., 1982). This indicates that in terms of depression-anxiety the mothers in the current sample are comparable to mothers of children with chronic illnesses.

Similar results were found for maternal distress, with all of the mothers in the current sample reporting significantly higher levels of distress related to being a parent compared to a normative population of mothers of children without a chronic illness, and similar levels of maternal distress compared to a normative population of mothers of children with myelodysplasia (Breslau et al., 1982). These findings are consistent with previous studies that have found higher levels of parenting stress in mothers of children with chronic illnesses compared to mothers of children without a chronic illness (Goldberg, Morris, Simmons, Fowler, & Levison, 1990; Quittner et al., 1992; Speltz, Armsden, & Clarren, 1990; Wysocki, Huxtable, Linscheid, & Wayne, 1989).

Mothers of children with cancer on treatment, epilepsy, and kidney disorders in the current sample reported significantly more time demands compared to a normative population of both mothers of children without a chronic illness as well as mothers of children with CF (Quittner et al., 1992). This suggests that mothers in the current sample perceive that their child's illness interferes with the mother's time for herself and her family more so than mothers in the normative population. This finding may be due to the timing of the current study. Mothers of children with cancer, epilepsy and kidney disorders were initially interviewed in during the last few weeks of the school year when there are additional activities and time demands placed on a parent.

In general, the psychological distress experienced by caregivers in the current study was consistent with normative caregiver populations, and was significantly higher compared to mothers of children without chronic illnesses. These findings are consistent with previous studies that examine the impact of caregiving.

### Caregiver Burden Model

In general, the results from this study provide empirical support for the proposed caregiver burden model (Figure 1). Demographic variables (child's sex and illness group) significantly predicted objective stress (the frequency and duration of medically related caregiving activities). Objective stress significantly predicted subjective stress (the perceived stress related to caregiving activities), while subjective stress was found to be a significant predictor of all four outcome variables (overload, depression-anxiety, maternal distress, and recreational activity time). However, objective stress was found to have only an indirect effect on psychosocial outcomes through subjective stress. The following is a discussion of the specific relationships between the parts of the model. The findings provide information about how caregiver burden impacts mothers and in turn, which mothers should be targeted for interventions to alleviate caregiver burden.

Objective Stress. As expected, illness group was a significant predictor of both caregiving frequency and caregiving duration. Mothers of children with cancer not on treatment participated in significantly fewer caregiving activities than the other illness groups. Most children with cancer who are in remission require very little in terms of medical care (e.g., infrequent doctor appointments, minimal maintenance medication). However, the actual time spent in caregiving for mothers of children with cancer not on treatment was not significantly different from mothers of children with epilepsy or asthma. This suggests that although there are fewer tasks for mothers of children with cancer not on treatment to perform, they still are required to spend time each week caring for their child's medical needs.

Mothers of children with cancer on treatment and kidney disorders spent over five hours per week in caregiving activities, while mothers in the other groups only spent

approximately two to three hours per week in caregiving activities. Mothers of all children with chronic illnesses are required to perform additional caregiving above and beyond normal parenting. Thus interventions aimed at alleviating caregiver burden are indicated for all illness groups. However, mothers of children with cancer on treatment and mothers of children with kidney disorders may benefit more from interventions that aim to reduce the amount of time spent in caregiving activities.

Child's sex was an unexpected predictor of caregiving frequency and caregiving duration, with mothers of male children reporting significantly more objective stress than mothers of female children. This finding is difficult to explain as child's sex has not been examined as a risk factor in the parenting stress literature. More specifically, studies that have measured illness-related caregiving tasks did not examine differences that may result from the child's sex (Quittner et al., 1992; Thompson et al., 1992). In addition, studies that have examined more global measures of burden (e.g., parenting stress, depression) in mothers of children with chronic illnesses did not examine the role that child's sex may play in negative outcomes (Breslau et al., 1982; Fielding et al., 1985; Hodges et al., 1985).

One possible explanation for the sex differences found in this study may be that male children are less cooperative and/or compliant with medical procedures, making the mother's caregiving job more difficult. Another possibility is that girls mature sooner than boys do, with female children taking more responsibility for their own medical management, alleviating some of the mother's caregiver burden. This area needs to be studied further but the results from the current study suggest that mothers of male children may need additional interventions to help reduce caregiver burden.

Due to their developmental level, younger children typically require more caregiving than older children. However, in this study, child's age was not found to be a significant predictor of objective stress. This may be due to the fact that child's age was confounded by disease group (cancer on treatment and asthma were younger than other illness groups), thus child age effects may have been masked by the significant illness group effect.

Disease duration was also expected to predict objective stress, with shorter disease duration related to greater objective stress. However, due to the small number of campers diagnosed within the last two years ( $n = 30$ ), there may not have been sufficient power to detect this relationship. In addition, disease duration was confounded with illness group, with cancer accounting for 60% of those diagnosed within the last two years.

It is also important to note that although illness group and child's sex were significant predictors of both caregiving frequency and caregiving duration, the total variance accounted for in these two models was 14% and 12% respectively. This suggests that there are a number of other factors not measured in this study that may contribute to objective stress. For example, illness severity and access to disease related resources may also contribute to objective stress (Pearlin et al., 1990; Wallander et al., 1989). In addition, as discussed earlier, variability within illness group also contributes to objective stress; thus prescribed treatment regimen may be a more accurate predictor of objective stress than type of illness.

Subjective Stress. Objective stress, in turn, predicted subjective stress related to caring for the child's illness. As expected, mothers who engaged in more caregiving



activities and spent more time in caregiving activities perceived greater stress related to caregiving. Demographic variables that predicted subjective stress included illness group and maternal race. Mothers of children with cancer on treatment and mothers of children with asthma perceived more caregiving stress than mothers of children with cancer not on treatment. The differences between illness groups in both objective and subjective stress indicate that caregiver burden is not experienced the same by all mothers of children with chronic illnesses. This is important for psychologists and other mental health care professionals who work with mothers of children with chronic illnesses, highlighting the importance of disease specific interventions.

An unexpected predictor of subjective stress was maternal race. African-American mothers reported more caregiving stress than Caucasian mothers, even though African-American mothers did not report more objective stress. However, studies of parenting stress or other negative outcomes have not examined the relationship between race and caregiving stress (Fielding et al., 1985; Hodges et al., 1985; Quittner et al., 1992).

The results from this study suggests that African-American mothers perceive their role as a caregiver to be more stressful than Caucasian mothers, placing them at greater risk for the negative consequences of caregiver burden. This finding also provides information to camp recruiters and other respite care program organizers, suggesting the need to target African-American mothers for interventions to help alleviate the caregiver stress they experience.

The final subjective stress model accounted for more variance than the objective stress models. However, only 26% of the variance for subjective stress was accounted



for by objective stress, illness group, and maternal race. Clearly there are additional variables accounting for the remainder of the variance, suggesting that what a mother is required to do to care for her child's illness is not the only factor contributing to caregiver stress.

Pearlin's model suggests that both social support and coping styles also contribute to caregiving stress (Pearlin et al., 1990). This study did not include a sensitive measure of social support. Although we considered the percent of time mothers consider themselves the primary caretaker an estimate of social support, this variable did not take into consideration the breakdown of caregiving duties. As discussed previously, some caregiving activities are more stressful than others. For example, fathers may be administering medications while mothers provide all of the nighttime care.

Outcomes. Objective stress did not significantly predict any of the outcome variables. This suggests that caregiving frequency and caregiving duration do not directly impact overload, depression-anxiety or maternal distress. However, as discussed below, caregiving stress significantly predicted overload, depression-anxiety and maternal distress. This would suggest that the number of caregiving activities a mother performs and the amount of time she spends in caregiving does not directly impact feelings of burnout and fatigue, depression and anxiety symptoms, or distress related to being a parent. Rather it is a mother's perception of how stressful caregiving is in her life that leads to negative outcomes.

There was a marginal effect suggesting that mothers who perform more caregiving activities spend less time in recreational activities. This suggests that the number of things a mother does to care for her child's illness may disrupt her schedule in

such a way that she does not have the time or energy to engage in recreational activities. For example, mothers who have to attend more frequent medical appointments or get up more often during the night may have less time or energy to participate in recreational activities.

In addition to caregiving frequency, employment status and illness group also predicted recreational activity time. Mothers who are not employed spent more time in recreational activities. Mothers who are employed likely have less free time during the day to pursue recreational activities.

Mothers of children with asthma spent more time in recreational activities than mothers of all other illnesses. This difference may be a result of the time in the summer when the interviews were conducted. The cancer, epilepsy, and kidney sessions were the first three of the summer, so the pre-camp interview occurred during the end of the school year when there is less time for recreational activities due to end of the year events (e.g., exams, class parties, school concerts). The asthma session on the other hand occurred late in the summer, thus the pre-camp interview fell during the middle of the summer. Consequently, the asthma effect simply may be a function of timing of the camp session rather than a function of the illness per se. The final recreational activity model (employment status, asthma, and caregiving frequency) only accounts for 6% of the total variance. This suggests that there are additional factors contributing to recreational activity time (e.g., access to activities, use of downtime to rest versus engaging in an activity).

As previously mentioned, subjective stress was a significant predictor of all four outcome variables: overload, depression-anxiety, maternal distress, and recreational

activity time. This suggests that the perceived level of stress related to caring for a child with a chronic illness, regardless of the actual number of caregiving tasks or the time spent in caregiving tasks, is related to negative outcomes. Thus, mothers who perceive higher levels of stress related to caring for their child's illness experience more negative psychosocial outcomes.

The relationship between subjective stress and the outcome variables is an important finding. Subjective stress appears to play an important role in terms of psychological outcomes, much more so than objective stress. This finding suggests that the measurement of caregiver burden in pediatric populations should not simply rely on what is required to care for a particular illness in terms of caregiving activities and time spent in caregiving.

In addition to subjective stress, overload was also predicted by the percent of time mothers perceive themselves to be the primary caregiver, with mothers who report a higher percent (e.g., 100% of the time vs. 50% of the time) also reporting more overload. Thus, mothers who do not share their caregiving duties with a spouse or other caretaker are at risk for experiencing greater feelings of burnout and fatigue due to caregiving. This is consistent with previous studies that have found spouse support to reduce the level of negative outcomes (e.g., depression, parenting stress) in mothers of children with chronic illnesses (Quittner, Gluckauf, & Jackson, 1990; Thompson & Gustafson, 1996b; Wallander et al., 1989) and developmental delays (McKinney & Peterson, 1987).

Along with caregiving stress, depression-anxiety scores were predicted by maternal employment status and maternal race. These results indicate that mothers who were currently not employed experienced more symptoms of depression and anxiety than

mothers who were employed. This is consistent with previous findings that regardless of child's illness or family SES, mothers not employed outside the home had higher levels of depression than employed mothers (Walker, Ortiz-Valdes, & Newbrough, 1989).

African-American mothers also reported significantly more symptoms of depression and anxiety than Caucasian mothers. Using the same measure, Breslau and colleagues (1982) found that Caucasian mothers had higher depression-anxiety scores than African-American mothers. In light of this difference in findings, as well as the fact that African-American mothers also reported greater caregiving stress is of concern. Perhaps these mothers do not feel as if they receive adequate support from the medical community in terms of managing their child's illness, which in turn leads to increased feelings of depression and anxiety. Due to the racial homogeneity of many chronic illnesses (e.g., CF, type 1 diabetes, sickle cell disease), racial differences in maternal caregiving stress have not been fully explored. The results from this study indicate that racial differences in caregivers need to be considered in order to provide the most effective interventions to alleviate caregiver burden.

In addition to subjective stress, maternal distress was significantly predicted by illness group, with mothers of children with asthma reporting significantly lower distress related to being a parent than mothers of all other illness groups. It is interesting to note that although mothers of children with asthma reported significantly more stress related to being a caregiver, they reported significantly less stress related to being a mother. As discussed previously, although asthma requires a strict regimen of preventative medications, when an asthma attack occurs, this can be life threatening. Therefore, the stress related to administering medication, especially in a time of crisis, may increase a

mother's level of caregiving stress. However, when a child's asthma is under control, it plays a small role in the day to day experience of mothers. These results support previous findings that the stress related to being a parent and being a caregiver of a chronically ill child may differ, requiring distinct measurement approaches (Quittner et al., 1990; Thompson et al., 1992).

In addition to maternal employment status and illness group (discussed previously), subjective stress was a significant predictor of recreational activity time. This suggests that mothers who felt less stressed about their caregiving responsibilities spent more time in recreational activities. To clarify this result, time spent in activities was divided into quartiles: the top 25% spent more than 48 hours per week in recreational activities and reported an average caregiving stress level of 5.4; the bottom 25% spent less than 18 hours per week in recreational activities and reported an average stress level of 11.6.

The results of this study did not provide support for the mediator model. When caregiving stress was added to the model, both caregiving frequency and caregiving stress became non-significant due to multicollinearity. Instead, objective stress appears to have an indirect effect on the outcome variables through subjective stress. As mentioned previously, this indirect effect highlights the importance of subjective stress as an indicator of caregiver burden. Regardless of how much a mother has to do to care for her child's illness, it is how stressful she perceives this caregiving experience to be that can lead to negative outcomes.

### Camp Generated Respite Care

As expected, objective stress remained at baseline levels one week and one month after the child returned home from camp. However, there were significant illness group differences in terms of objective stress, with mothers of children with asthma reporting an increase in the frequency of caregiving tasks both one week and one month after the child returned home from camp. Asthma camp is the only week of the summer that involves disease specific education. In addition, during the asthma session at BCGC, all campers are given a peak flow meter and are required to monitor their pulmonary functioning twice a day. The finding that the number of caregiving activities increased after camp suggests that children continued to monitor their peak flow readings after camp. In other words, while attending camp children learned an additional skill that is used to care for their asthma. When campers returned home, if they continued to check their peak flow readings, this additional caregiving task could lead to the increase in caregiving frequency observed in this study.

Duration of caregiving activities was also found to remain around baseline levels for all groups one week and one month after the child returned home from camp, however the amount of time spent in caregiving activities was significantly different for the illness groups, with mothers of children with cancer on treatment and kidney disorders spending the most amount of time caring for their child's illness before and after camp. This study assumed that while the child was at camp mothers experienced respite care by not having to care for their child's medical illness. As expected, the week of respite care did not change objective stress one week and one month after the child returned home from camp. This is because the child's illness, and the related caregiving duties, did not change while the child was at camp.



Similar to frequency and duration of caregiving, stress directly related to caregiving was not significantly different one week and one month after camp. This finding was unexpected. Although caregiving duties did not change when the child returned home from camp, it was expected that after a week of respite care, mothers would feel that caregiving was less stressful than before their child attended camp.

A significant illness group difference regardless of time was found for the stress related to caregiving duties, with mothers of children with asthma ( $M = 12.3$ ) and kidney disorders ( $M = 14.0$ ) experiencing on average a greater level of subjective stress than mothers in the other illness groups ( $M$ s range 3.9 to 10.2). As discussed previously, mothers of children with asthma may perceive more stress related to caregiving than other groups due to the stress that is often associated with the treatment of asthma attacks. Higher levels of perceived stress for mothers of children with kidney disorders might be caused by the number of caregiving activities and the amount of time required by certain treatment regimens. However, to clarify the relationship between medical regimens and perceived stress, a larger sample that is able to differentiate between they types of medical regimens (e.g., dialysis vs. medication management) is needed.

The effects of respite care were most notable in the observed changes in psychological distress variables and time spent in recreational activities, with effects maintained one week and up to one month after the child returned home from camp.

For overload, a significant interaction between illness group and time suggests that feelings of overload related to caregiving changed differently over time for each illness group. The decrease in overload scores during camp suggests that this week without caregiving provided respite care for mothers. In addition, the benefit of reduced



feelings of burnout and fatigue related to caregiving was maintained up to one month after camp for all illness groups. In general, one month before camp overload scores were consistent with a normative population of AD caregivers (Pearlin et al., 1990). However, the benefits of respite care are highlighted by the fact that during camp, mothers in the current study reported significantly lower overload compared to the normative sample,  $T_{w(\text{full sample})} = -8.1, p < .01$ .

One month after camp, overload remained significantly below the normative population for mothers of children with cancer both on treatment,  $T_{w(\text{cancer on tx})} = -2.3, p < .01$ , and not on treatment,  $T_{w(\text{cancer no tx})} = -4.3, p < .01$ . This change is most notable for mothers of cancer on treatment who had reported significantly more overload than the normative population one month before camp. The ability to maintain the benefits of respite care for mothers of children with cancer may be related to the significantly shorter disease duration found in this group. Significant disruption has been found in families of children newly diagnosed with cancer (Dahlquist et al., 1993; Manne et al., 1995). A week of respite care may serve as a reminder for mothers of what life was like prior to their child's diagnosis, and in turn, may result in less burnout and fatigue. In addition, overload in this study was defined as the burden and fatigue caused by the relentless nature of caregiving. Thus, caregiving may not feel as relentless to mothers of children with cancer since they have been caregivers for a shorter period of time compared to mothers of more chronic illnesses.

The effect of respite care can also be seen in significantly lower depression-anxiety scores while the child was at camp, with scores decreasing to a level where mothers in this were comparable to a normative population of mothers of healthy children

(Breslau et al., 1982). In addition, one month after camp depression-anxiety scores remained consistent with the healthy normative population.

A significant interaction between illness group and time for maternal distress suggests that the stress related to being a parent changed differently over time for each illness group. Mothers of children with cancer not on treatment maintained the benefits of reduced maternal distress for up to one month after camp while mothers of children with kidney disorders did not maintain the reduced level of maternal distress one week and one month after camp. The different maintenance effects highlight how the impact of respite care differs depending on illness group. Mothers of children with cancer not on treatment were likely able to maintain benefits because they have significantly fewer caregiving requirements than mothers of children with other illnesses. Lower maternal distress scores during camp suggest that mothers of children with kidney disorders benefited during the week of respite care. However, due to the caregiving demands placed on these mothers after camp, this benefit is not maintained.

During camp, maternal distress scores had decreased to a level that was consistent with mothers of healthy children, with the exception of mothers of children with cancer on treatment,  $T_w(\text{cancer on tx}) = 2.6$ ,  $p = .02$ , and epilepsy,  $T_w(\text{epilepsy}) = 2.3$ ,  $p = .03$  (Breslau et al., 1982). One month after camp, maternal distress scores were also consistent with the healthy normative population with the exception of mothers of children with kidney disorders,  $T_w(\text{kidney}) = 2.6$ ,  $p = .02$ .

The amount of time spent in recreational activities also varied over time for each illness group. Although significant changes in recreational activity time occurred during camp, contrary to the hypothesis the amount of time spent in recreational activities during

camp decreased below baseline levels for epilepsy, asthma and cancer not on treatment groups. Mothers of children with cancer on treatment and kidney disorders reported more time spent in recreational activities during camp.

The differences between the groups of mothers who increased versus decreased the amount of time spent in recreational activities may be due to the perceived levels of caregiving stress mothers experienced before camp. Those mothers that reported lower levels of stress before camp (epilepsy, asthma, and cancer not on treatment) spent less time in recreational activities while their child was away. It is possible that since these mothers perceived less stress related to caring for their child's illness to begin with, they may not have felt as compelled to fill their free time with activities during their break from caregiving, choosing instead to rest and relax. One variable not measured in the structured interview was the amount of time mothers spent sleeping or napping. Mothers of children with cancer on treatment and kidney disorders demonstrated the hypothesized effect of respite care: spending significantly more time in recreational activities during camp. Although mothers of children with kidney disorders decreased to below baseline one week after camp, the maintenance of respite care benefits was demonstrated by the cancer on treatment and kidney groups, with recreational activity time remaining above baseline levels up to one month after the child returned home from camp.

Time Demands. The long-term benefit of respite care appears to have generalized to more stable traits for all illness groups, with a significant decrease in mothers' perception that caregiving interfered with her time for herself and her family, as well as with her personal growth and development, with mothers reporting less interference one month after the respite care. Time demands scores one month after the end of camp were

consistent with the normative population of mothers of children without a chronic illness (Quittner et al., 1992). However, compared to the normative group of mothers of children with CF, mothers of children with epilepsy,  $T_w(\text{epilepsy}) = 2.2$ ,  $p = .03$ , and kidney disorders,  $T_w(\text{kidney}) = 2.4$ ,  $p = .03$ , continue to report significantly greater time demands. For the epilepsy group, this difference may be explained by the relationship between the questions asked and the nature of the illness. For example, mothers are asked about the amount of time spent watching their child, which would be more for mothers of children with epilepsy who are constantly monitoring their children for seizures. In addition, many children with epilepsy have developmental delays that may place more demands on a mother's time. In this study it appears that mothers of children with kidney disorders experience significantly more caregiver burden which would impact the amount of time they have for themselves and their families.

#### Camp Generated Respite for Each Illness Group

As the results indicate that caregiver burden had a different impact on mothers of children with different types of illnesses, changes in objective stress, subjective stress, and outcomes were examined independently for each illness group.

Cancer. Due to the small sample size for mothers of children with cancer on treatment, there may not have been enough power to detect interactions between time and both the caregiver burden variables and the outcome variables. However, an examination of the standardized means suggests that for mothers of children with cancer on treatment, caregiving duration increased one week post-camp while caregiving stress decreased. This suggests that although mothers of children with cancer on treatment spent more time in caregiving activities after camp ended, they perceived caregiving to be less stressful.

Overload and depression-anxiety scores decreased during camp, with both scores remaining below baseline one week and one month after camp. However, maternal distress increased during camp, decreasing to below baseline levels one week and one month after camp. This suggests that although respite care may alleviate feelings of overload and depression-anxiety during camp, mothers experienced more distress related to being a parent while their child was away. Due to the shorter disease duration found in this group, it is reasonable that these mothers experienced increased maternal stress during the week that the child was at camp. This finding is especially salient when considering the types of questions asked with the maternal distress measure (e.g., over the past week did you feel worried, tense).

As expected, recreational activity time increased while the child was at camp, with recreational activity time remaining above the baseline level for up to one month after camp. When examined together, the results for mothers of children with cancer on treatment provide additional support for the argument that caregiver burden is caused directly by the perceived stress related to caregiving rather than the amount of time mothers spend in caregiving activities. Although mothers of children with cancer on treatment reported longer caregiving duration after camp, caregiving stress decreased after camp. In turn, the change in perceived stress directly impacted outcome variables, with lower levels of overload, depression-anxiety, and maternal distress, and more time spent in recreational activities one week and one month after camp.

Epilepsy. The caregiver burden variables changed differently over time for mothers of children with epilepsy. Contrary to the hypothesis, caregiving frequency decreased one week after camp, remaining below baseline one month after camp.

However, caregiving duration and caregiving stress were above baseline levels one week after camp. One month after camp ended caregiving duration returned to baseline levels while caregiving stress remained above baseline. Although mothers of children with epilepsy were involved in fewer caregiving activities, mothers still perceived the same level of caregiving stress, suggesting that the benefits of respite care for this group did not carry over after camp. In fact, mothers may have enjoyed their week without caregiving so much, that it seemed more stressful to be a caregiver once the child returned home from camp compared to one month before the child attended camp.

Although the outcome variables were found to differ significantly from one another, an examination of the means suggests that changes in the psychological distress variables followed the expected pattern of change. Overload, depression-anxiety, and maternal distress all decreased during camp, and remained below baseline levels up to one month after camp. Recreational activity time was hypothesized to increase as an effect of respite care, however, this was not found for mothers of children with epilepsy. In general, this group has fewer caregiving responsibilities, resulting in low levels of caregiver stress. Therefore, they may have spent their respite care time resting and relaxing rather than engaging in recreational activities. All of the outcome variables decreased from one month before camp to one month after camp, suggesting that not only did camp provide respite care for mothers of children with epilepsy, but that the benefits were maintained longitudinally. Thus, this group may require less frequent respite care interventions than other illness groups.

Kidney. Due to the small sample size, there was insufficient power to detect significant effects for mothers of children with kidney disorders. An examination of the



means suggests that one week after camp caregiving frequency and duration were below baseline, while caregiving stress maintained around the baseline level. One month after camp, all three caregiver burden variables had decreased. As dialysis treatments would not have changed after camp, it is possible that children with kidney disorders may have become more self-sufficient in terms of medication compliance after camp. However, the change in these variables is small and warrants further investigation with larger samples.

The benefits of respite care for mothers of children with kidney disorders may be demonstrated more by the outcome variables. Overload, depression-anxiety, and maternal distress all decreased while the child was at camp, returning to near baseline levels one week after camp and remaining near baseline one month after camp. Respite care appears to have provided mothers the opportunity to spend more time in recreational activities, with recreational activity time increasing during camp. However, as with the psychological distress variables, recreational activity time returned to and remained near baseline levels one week and one month after camp. Mothers of children with kidney disorders appear to have benefited from a week of respite care, however, these positive changes were not maintained after the camp session ended. This indicates that mothers of children with kidney disorders may benefit from more frequent respite care.

Asthma. Changes in the caregiver burden variables for this group were extremely small, but demonstrate that while caregiving frequency increased one week and one month after camp, caregiving duration and caregiving stress maintained near baseline levels over time. As previously discussed, this effect may be due to an increase in peak flow monitoring after camp, a caregiving activity that requires little extra time and appears to result in no additional stress. The increase in peak flow monitoring



demonstrates that some disease specific learning and compliance with medical regimen may in fact carry over after the camp session ends. This differs from a previous study that found no maintenance of compliance to medical regimen after camp (Spevack, Johnson, Riley, & Silverstein, 1989). Yet without a specific measurement of the number of peak flow meter readings completed before and after camp, the findings from this study are not conclusive.

The outcome variables were found to differ over time. Overload decreased during camp while the depression-anxiety and maternal distress maintained near baseline levels. Overload and maternal distress maintained near baseline levels one week and one month after camp while depression-anxiety was above baseline one week and one month after camp. Contrary to expectations, time spent in recreational activities decreased while the child was at camp, with this effect maintaining one week and one month after camp ended. Together these results suggest that for mothers of children with asthma, camp provided respite care by alleviating the burnout and fatigue that results from caregiving, while not having an impact on depression-anxiety and maternal distress. However, one month before camp, mothers of children with asthma reported relatively low levels of depression-anxiety and maternal distress, comparable to the levels other illness groups reported after a week of respite care.

The decrease and maintenance of below baseline recreational activity time may be due to the type of caregiver burden experienced by these mothers. Although mothers of children with asthma on average perform 18 caregiving activities per week, they spend less than three hours per week in caregiving, allowing more time to engage in recreational activities. Thus when presented with a week of respite care, mothers of

children with asthma may have spent the time resting and relaxing. The maintenance of this decrease in recreational activities one week and one month after camp may be due to the timing of the interviews, with both follow-up interviews occurring during the first month of school. This time of year tends to be hectic for mothers, which may prevent them from engaging in recreational activities.

Cancer Not on Treatment. Due to the small sample size for mothers of children with cancer not on treatment, there may not have been enough power to detect interactions between time and both the caregiver burden variables and the outcome variables. However, an examination of the standardized means suggests that although caregiving frequency and caregiving duration were above baseline one week after the child returned home from camp, caregiving stress was below baseline levels one week after camp. Although mothers of children with cancer not on treatment were required to provide additional care after camp, their level of caregiver stress did not increase, supporting the hypothesis that respite care benefits would be maintained by decreasing subjective stress after camp. However, this effect was not found one month after camp as caregiving frequency and caregiving duration were below baseline levels while caregiving stress was near baseline.

The outcome variables changed differently over time for mothers of children with cancer not on treatment. Overload, depression-anxiety, and maternal distress were below baseline during camp, with effects maintained for all three variables one week after camp. As depression-anxiety scores returned to baseline one month after camp, overload and maternal distress remained below baseline one month after camp. This suggests that respite care benefits mothers of children with cancer not on treatment by reducing the

distress related to being both a caregiver and a mother for up to one month after camp ended, as well as reducing depression-anxiety symptoms for a shorter duration. It appears as if mothers of children with cancer not on treatment benefited for a long duration after respite care ended, thus they may not need interventions as frequently as mothers of children with other illnesses. Contrary to expectations, time spent in recreational activities decreased during camp, increased one week after camp, and decreased again to below baseline levels one month after camp. As seen in other illness groups with fewer caregiving demands and lower levels of overall caregiving stress, mothers of children with cancer not on treatment may have used the extra time from the respite care to rest rather than engage in activities.

#### Study Strengths

In terms of caregiver burden, there are multiple strengths in terms of the methodology of this study. First, the examination of caregiver burden is based on an adapted theoretical model that addresses the specific issues related to mothers of children with chronic illness. Second, this study compared four illness groups that have different requirements in terms of caregiving. Third, by using measures of disease specific burden (objective and subjective stress) we were able to examine the relationship between the caregiver burden variables and illness group. Finally, the inclusion of more general psychological distress measures allowed us to compare our sample to normative populations as well as examine the differences between disease specific caregiving stress and more general psychological distress. Previous studies have generally included only measures of general parenting stress or negative outcomes (e.g., depression). These

methodological strengths allowed us to provide empirical evidence supporting a theoretical caregiver burden model for mothers of children with chronic illnesses.

Strengths in methodology also contributed to the study of respite care as an intervention. By including multiple illness groups we were able to observe the benefits all mothers experienced regardless of illness type (e.g., decrease in overload during camp), while also examining differences between illness groups in terms of changes in caregiver burden variables and the maintenance of respite care benefits over time. By interviewing mothers both one week and one month after camp, we were able to observe both short term and longer lasting respite care benefits. This study supported the hypothesis that summer camps provide respite care for mothers, which allows us to conceptualize camps as more than just a place for kids to have fun.

#### Study Limitations

The limitations in this study include problems with sample size, a lack of some illness related information, measurement issues, the timing of the interviews, and small effects in the results. Although this study attempted to recruit enough subjects to ensure adequate power, significant differences between mothers of children with cancer on and off treatment were not expected. These differences demanded that mothers of children with cancer be divided into two smaller groups. In addition, the number of eligible campers with kidney disorders was much lower than the target number of 50 subjects, again resulting in a small group. This prevented us from examining differences in this group in terms of prescribed medical regimen. It would be expected that mothers of children that require dialysis experienced more caregiver burden than mothers of children who require only medication management. In terms of disease duration, only 17% of the

sample had been diagnosed within the last two years. This prevented us from detecting the impact of disease duration on caregiver burden and outcome variables.

Due to incomplete medical records, we were unable to obtain some disease specific information. Camp records only had asthma severity ratings from 67% of the campers. Some of the changes in caregiver burden variables may have differed for those mothers of children with severe asthma as compared to mothers of children with mild asthma. Similarly, for children with epilepsy, camp records did not have information about seizure history or seizure frequency. Comparing mothers of children who have frequent seizures (up to several times per day) with mothers of children who are seizure free may have highlighted caregiver burden differences within this illness group.

Although the structured interview assesses four areas of caregiver burden, this is by no means an exhaustive assessment of what mothers are required to do in terms of caregiving. For example, we did not measure the secondary caregiving activities than many mothers must engage in. For mothers of children with cancer on treatment, this may include helping a child who is vomiting due to chemotherapy. For mothers of children with epilepsy, this may include watching their seizures and providing comfort and support during and after a seizure occurs. For all mothers, additional caregiving activities could include dealing with insurance companies and scheduling appointments. Each of these secondary caregiving activities may have an impact on the frequency, duration, and stress related to caregiving.

The Recreational Activities Checklist only measured the amount of time mothers spent in recreational activities giving an estimate of time for each activity over the past week. This approach neglected the number of activities mothers engaged in. The

number of activities per day or per week may have provided additional useful information about the benefits of camp generated respite care on recreational activities. In addition, future checklists should include self-care activities (e.g., sleeping, napping, getting a manicure), as mothers may engage in these activities for a longer duration while their child is away. Although increased activity time was expected, this study shows that respite care may decrease involvement in recreational activities in favor of resting and relaxing. Finally, the RAC did not assess who mothers were with while participating in recreational activities. Previous results indicate that mothers may spend more time in activities away from the family while their child is at camp (Smith, Gotlieb, Gurwitsch, & Blotcky, 1987).

Methodologically the timing of the camp sessions made it difficult to compare differences between the illness groups. The cancer, epilepsy, and kidney camp sessions all occurred in June, with the pre-camp interview falling during the last few weeks of school and the post-camp interviews conducted in the middle of the summer. The asthma camp session was not until August, thus the pre-camp interview was in July, with the post-camp interviews falling during the first month of school. Thus some of the disease effects found in the study may have simply been a product of when the child went to camp and the relationship to other activities in their life (e.g., the end or beginning of the school year). It was impossible to disentangle timing of camp session from disease group in this study, as only one illness group attended each camp session. Future studies could address this problem by repeating the study with camp sessions that fall in a different order. If the findings from the current study were maintained in this situation, then we



could be more confident that the disease specific outcomes in question (e.g., recreational activity time) were due to the illness and not the timing of the camp session.

Finally, although the results from this study support the proposed caregiver burden model, only a small amount of variability was accounted for in the regression analyses. This suggests that additional variables are playing a role in caregiver burden. Studies that have examined the relationship between caregiving and outcomes have demonstrated that social support and coping style mediate the relationship between caregiving and negative outcomes (Pearlin et al., 1990; Quittner et al., 1990; Thompson et al., 1992; Wallander et al., 1989). Additional variables may include perception of competence, role restriction, marital satisfaction, and the relationship or level of conflict between mother and child (Pearlin et al., 1990; Wallander & Varni, 1998), as well as perception of hope and service utilization (Wallander & Varni, 1998).

#### Implications and Future Directions

This study provides two major conclusions: (1) caregiver burden exists in mothers of children with chronic illnesses, however caregiving activities were found to have an indirect effect on outcomes through subjective stress, and (2) a one week summer camp for children with chronic illnesses provided respite care for mothers, alleviating feelings of overload, symptoms of depression and anxiety, feelings of distress related to being a parent, perceived impact of caregiving on a mother's time, and changing the amount of time mothers spend in recreational activities while the child was at camp. Some changes in outcomes due to respite care were maintained for up to one month after camp ended.

Caregiver Burden. The caregiver burden model supported by this study suggests that certain demographic variables (illness type, child's sex) contribute to the level of



objective stress a caregiver experiences. In turn, objective stress (caregiving frequency and caregiving duration) significantly impacts subjective stress (perceived stress related to caregiving). However, contrary to expectations, objective stress does not have a direct impact on outcome variables, but rather an indirect effect through subjective stress. The relationship between subjective stress and outcomes suggests that it is not the number of caregiving tasks a mother must do or the amount of time mothers spend in caregiving, but rather how stressful she perceives this caregiving to be that impacts psychological distress and other outcomes.

The fact that subjective stress is really the important variable to consider when examining the impact of caregiver burden on outcomes is an important finding. Objective stress varies considerably between illness groups as well as within illness groups. Although objective stress is related to subjective stress, two groups of caregivers that perform the same caregiving duties may perceive different levels of caregiving stress. For example, in the current study, mothers of children with epilepsy and asthma performed a similar number of caregiving activities, but reported significantly different levels of stress. In this case, it would be important to examine additional disease specific issues (e.g., illness severity, treatment of asthma attacks versus seizures). Future studies should examine additional variables that may contribute to differences in terms of perceived stress. For example, the literature suggests that mothers who have more social support perceive caregiving as less stressful compared to mothers who have limited social support (Pearlin et al., 1990; Quittner et al., 1990; Wallander et al., 1989).

Differences between the illness groups for reported objective stress and subjective stress were found, supporting the conclusion that additional studies need to examine

additional variables that may contribute to feelings of subjective stress. In the current study, mothers of children with cancer on treatment and kidney disorders performed significantly more caregiving duties that required significantly more time than mothers of children with cancer not on treatment and epilepsy. In this case, mothers who are performing different caregiving duties reported similar levels of caregiving stress. However, mothers of children with epilepsy and asthma are required to perform a similar number of caregiving tasks that require a comparable amount of time, while mothers of children with asthma reported significantly higher levels of stress related to caregiving. An examination of disease specific variables (in this case types of treatment) may elucidate that fact that since the treatment of asthma can include frequent crises, caregiving may end up being more stressful for this group of mothers.

These findings emphasize the importance of studying illness groups individually rather than grouping them altogether. The field of pediatric psychology has moved toward a more disease specific approach in terms of research and intervention in recent years due to differences such as the ones reported here. Specifically the results from this study suggest that mothers of children with cancer on treatment and kidney disorders may need more ongoing caregiver support and more frequent respite care as these group appears to be experiencing the greatest levels of stress and negative outcomes. However, the inclusion of multiple illness groups in this study raised two issues that have been understudied, namely the role of maternal race and child sex on caregiver burden. It is possible that when studying illnesses that have a homogeneity of race, the impact of caregiving will be masked. In addition, child's sex may influence the mother child

relationship, which indirectly influences the level of perceived stress mothers may experience.

Future studies should continue to examine and define caregiver burden in mothers, as this area has been understudied in the pediatric psychology literature. Additional factors that contribute to caregiver burden need to be examined, including social support, maternal race, and child's sex.

Respite Care. The fact that camp provides respite care for mothers is important on multiple fronts. Camps can now be conceptualized differently. Rather than only thinking of camps as a place for kids to go for a week of fun, camps can be conceptualized as one type of respite care that can provide services for mothers. This rethinking of what camp does for children and their families influences how we provide services to mothers. Providing referrals to summer camps for children with chronic illnesses should be incorporated into the psychological treatment of children and their families.

The fact that summer camps for children with chronic illnesses already exist make them an ideal intervention to alleviate caregiver burden. The utilization of these programs for respite care is an affordable way to provide simultaneous respite care services to many mothers. In addition, camps can reach mothers in a large geographical area, assisting those mothers who may live in an area where weekly respite care services may not exist.

Respite care funding is variable, but what funding there is could be applied to summer camps by recognizing that these programs provide respite care services. For example, with the passage of the Children's Justice Act (Public Law 99-401) and it's

amendment, the Children's with Disability Temporary Care Reauthorization Act (P.L. 101-127), respite care has gained support at the federal level. Additional funding is available in over 30 states, as well as through Medicaid waivers. The utilization of respite care funding would allow for additional camping programs, as well as more frequent programs, which in turn would allow for the maintenance of respite care benefits over time. For camps like Boggy Creek that rely on private donors, the data provided in this study allow fundraisers to provide their patrons with empirical evidence that camp is more than a place for children simply to have fun.

In addition to camp, other interventions should be used to provide short-term relief from caregiving, alleviating the stress and burden many mothers appear to experience. The benefits of the respite care provided by summer camp in this study were maintained for up to one month in the current study, with some illness groups experiencing the benefits of respite care for an even shorter duration of time. However, future studies should consider a combination of respite care approaches for the most effective intervention (e.g., weekly in-home care allowing mothers to catch up on errands, monthly evening care to allow mothers to go out socially, annual summer camp to allow mothers a vacation). The camp where this study was conducted also runs family weekends during the school year, where the entire family attends camp. These family weekends may also serve as "booster sessions" for mothers who experienced respite care during the summer.

This study supported a theoretical model of caregiver burden in pediatric populations. This model suggests that the level of perceived stress related to caregiving that has a more direct impact on psychosocial outcomes rather than the caregiving duties

required to manage the child's illness. Respite care in the form of a summer camp for children with chronic illnesses provides a short term break from caregiving, alleviating caregiver burden while the child is at camp, with this relief maintained for up to one month after camp ends.

# APPENDIX A STRUCTURED INTERVIEW OUTLINE

## Medications

- Did your child take any medications yesterday? **Yes No**  
*If yes, continue, if no, go on to weekly question*

- How many times? **1 2 3 other**\_\_\_\_\_

Please think about the first time your child took medications yesterday...

- Were you involved when your child took their medication? (e.g., reminding, supervision, or actual help in taking medications)

**Yes No**

*If yes,*

- How long did it take and how stressful was it for you?

		Stressful			
		Not at all			Extremely
_____minutes		0	1	2	3 4

Now think about the second time your child took medications yesterday...

- Were you involved when your child took their medication? (e.g., reminding, supervision, or actual help in taking medications)

**Yes No**

*If yes,*

- How long did it take and how stressful was it for you?

		Stressful			
		Not at all			Extremely
_____minutes		0	1	2	3 4

Please think about the third time your child took medications yesterday...

- Were you involved when your child took their medication? (e.g., reminding, supervision, or actual help in taking medications)

**Yes No**

If yes,

- How long did it take and how stressful was it for you?

		Stressful				
		Not at all				Extremely
_____ minutes		0	1	2	3	4

- Is this what happens everyday in terms of your child's medications?    **Yes**    **No**

If no,

- What made this day different than everyday?

\_\_\_\_\_

### Weekly Medications

- During the past week, did your child take any (or any additional) medications?

**Yes**    **No** (if no, continue with next section)

If yes,

- How often? \_\_\_\_\_

The interviewer then asked the mothers to recall one-by-one the times their child took their medications, gathering the following information for each time.

- Were you involved when your child took their medication? (e.g., reminding, supervision, or actual help in taking medications)

**Yes**    **No** (skip to next section)

- How long did it take and how stressful was it for you?

		Stressful				
		Not at all				Extremely
Time 1	_____ minutes	0	1	2	3	4
Time 2	_____ minutes	0	1	2	3	4
Time 3	_____ minutes	0	1	2	3	4
Time 4	_____ minutes	0	1	2	3	4
Time 5	_____ minutes	0	1	2	3	4



Home Medical Procedures

- Other than medications, did your child require any type of medical procedure at home yesterday (e.g., dialysis, peak flow monitoring)? **Yes No**

*If yes, continue, if no, go on to next*

*page*

- How many times?    **1      2      3      other \_\_\_\_\_**

Please think about the first time your child performed this procedure yesterday...

- Were you involved with the child's procedure? (e.g., reminding, supervision, or actual help in taking medications)

**Yes No**

*If yes,*

- How long did it take and how stressful was it for you?

		Stressful					
		Not at all				Extremely	
_____ minutes		0	1	2	3	4	

Now think about the second time your child performed this procedure yesterday...

- Were you involved with the child's procedure? (e.g., reminding, supervision, or actual help in taking medications)

**Yes No**

*If yes,*

- How long did it take and how stressful was it for you?

		Stressful					
		Not at all				Extremely	
_____ minutes		0	1	2	3	4	

Please think about the third time your child performed this procedure yesterday...

- Were you involved with the child's procedure? (e.g., reminding, supervision, or actual help in taking medications)

**Yes No**

*If yes,*

- How long did it take and how stressful was it for you?

		Stressful					
		Not at all				Extremely	
_____ minutes		0	1	2	3	4	



### Medical Care Outside Home

- During the past week, did your child require any medical care outside of the home (e.g., doctor's appointments, other medical appointments, hospitalizations)?

**Yes**      **No** (*skip section*)

1. How many appointments this week

Please describe the first appointment your child had

- How long did this appointment last (including waiting room time)? \_\_\_\_\_ minutes
- Did you attend the appointment and wait with child? **Yes** **No**
- Did you drive your child to this appointment? **Yes** **No**  
Driving time roundtrip  
\_\_\_\_\_ minutes
- Overall, how stressful was this for you (the appointment, driving, parking, etc.)?  
Not at all 0 1 2 3 4 Extremely

Please describe the second appointment your child had

- How long did this appointment last (including waiting room time)? \_\_\_\_\_ minutes
- Did you attend the appointment and wait with child? **Yes** **No**
- Did you drive your child to this appointment? **Yes** **No**  
Driving time roundtrip \_\_\_\_\_ minutes
- Overall, how stressful was this for you (the appointment, driving, parking, etc.)?  
Not at all 0 1 2 3 4 Extremely

Nighttime Care

During the last week,

- Did you have to wake up during the night to attend to your child's medical needs?

Yes No (skip section)

- How often during the week did you wake up? 1 2 3 other \_\_\_\_\_

Please describe the first time you had to wake up to attend to your child's medical needs

---

- How long did it take for you to take care of your child? \_\_\_\_\_ minutes

- How long did it take for you to fall back asleep after caring for your child?  
\_\_\_\_\_ minutes

- How stressful was it for you to get up during the night?

Not at all 0 1 2 3 4 Extremely

Please describe the second time you had to wake up to attend to your child's medical needs

---

- How long did it take for you to take care of your child? \_\_\_\_\_ minutes

- How long did it take for you to fall back asleep after caring for your child?  
\_\_\_\_\_ minutes

- How stressful was it for you to get up during the night?

Not at all 0 1 2 3 4 Extremely

Please describe the third time you had to wake up to attend to your child's medical needs

---

- How long did it take for you to take care of your child? \_\_\_\_\_ minutes

- How long did it take for you to fall back asleep after caring for your child?  
\_\_\_\_\_ minutes

- How stressful was it for you to get up during the night?

Not at all 0 1 2 3 4 Extremely

APPENDIX B  
OVERLOAD, DEPRESSION-ANXIETY, MATERNAL DISTRESS

**Caregiver Overload**

- I am going to read you some statements about your energy level and the time it takes to do the things you have to do. How much does each statement describe you?
- (a) You are exhausted when you go to bed at night
- 4 - Completely describes you
  - 3 - Describes you quite a bit
  - 2 - Somewhat describes you
  - 1 - Does not describe you at all
- (b) You have more things to do than you can handle
- 4 - Completely describes you
  - 3 - Describes you quite a bit
  - 2 - Somewhat describes you
  - 1 - Does not describe you at all
- (c) You don't have time just for yourself
- 4 - Completely describes you
  - 3 - Describes you quite a bit
  - 2 - Somewhat describes you
  - 1 - Does not describe you at all
- (d) You work hard as a caregiver but never seem to make any progress
- 4 - Completely describes you
  - 3 - Describes you quite a bit
  - 2 - Somewhat describes you
  - 1 - Does not describe you at all

**Depression-Anxiety**

- Now I'm going to ask you a series of questions and I want you to think back about the previous week
1. Did you have periods of days where you couldn't take care of things because you couldn't "get going"?
- Yes                      No
2. In general, would you say that during most of the week you were in
- Very good spirits      Good spirits      Low spirits      Very low spirits**

3. Did you have periods of such great restlessness that you could not sit long in a chair?      **Yes**      **No**
4. Did you worry?      **Yes**      **No**
5. Were you bothered by nervousness (i.e., being irritable, fidgety, or tense)?      **Yes**      **No**
6. Did you feel apart or alone, even among friends?      **Yes**      **No**

### Maternal Distress

- Next I'm going to read you some unpleasant feelings that many women who are mothers sometimes experience. When you think of your experience as a parent, how much do you feel

- |                          |                |               |                    |                 |
|--------------------------|----------------|---------------|--------------------|-----------------|
| (a) Frustrated           | Very Much<br>4 | Somewhat<br>3 | Just a little<br>2 | Not at all<br>1 |
| (b) Tense                | Very Much<br>4 | Somewhat<br>3 | Just a little<br>2 | Not at all<br>1 |
| (c) Worried              | Very Much<br>4 | Somewhat<br>3 | Just a little<br>2 | Not at all<br>1 |
| (d) Bothered             | Very Much<br>4 | Somewhat<br>3 | Just a little<br>2 | Not at all<br>1 |
| (e) Unhappy              | Very Much<br>4 | Somewhat<br>3 | Just a little<br>2 | Not at all<br>1 |
| (f) Emotionally worn out | Very Much<br>4 | Somewhat<br>3 | Just a little<br>2 | Not at all<br>1 |
| (g) Unsure of yourself   | Very Much<br>4 | Somewhat<br>3 | Just a little<br>2 | Not at all<br>1 |

APPENDIX C  
EXCESS TIME DEMANDS SCALE

- For the next set of questions I want you to think back to the past month. Your response choices are true/false.
1. I always watch to make sure my child does not do physical harm to himself/herself or others
  2. When my child is not well, I can't go out
  3. I get out of the house to do something interesting at least once a week
  4. I have given up things I have really wanted to do in order to care for my child
  5. I can go visit with friends whenever I want
  6. Sometimes I need to get away from the house
  7. I have no time to give the other members of the family
  8. I have enough time to myself
  9. The constant demands to care for my child limit my growth and development
  10. I have had to give up a chance for a job because of my child
  11. Outside activities would be easier without my child
  12. Most of my child's care falls on me
  13. I have had chances to carry on interests outside the home
  14. My child's needs come first



# APPENDIX D RECREATIONAL ACTIVITIES CHECKLIST

1. Yesterday, did you watch television/videos? Yes    No
  - For how long? \_\_\_\_\_minutes
  - If that typical for you? Yes    No
- If no, do you usually watch **more** or **less**?
  - Please estimate the amount of time over the past week you spent watching television/videos \_\_\_\_\_minutes
  
2. Yesterday did you read (books, newspaper, etc.) Yes    No
  - For how long? \_\_\_\_\_minutes
  - If that typical for you? Yes    No
- If no, do you usually read **more** or **less**?
  - Please estimate the amount of time over the past week you spent reading \_\_\_\_\_minutes
  
3. Yesterday did you use the computer for non-work related activities (i.e., games, internet) Yes    No
  - For how long? \_\_\_\_\_minutes
  - If that typical for you? Yes    No
- If no, do you usually use the computer **more** or **less**?
  - Please estimate the amount of time over the past week you spent using the computer for non-work related activities \_\_\_\_\_minutes
  
4. Yesterday did you talk on the phone with friends or relatives? Yes    No
  - For how long? \_\_\_\_\_minutes
  - If that typical for you? Yes    No
- If no, do you usually talk on the phone **more** or **less**?
  - Please estimate the amount of time you spend talking on the phone with friends or relatives over the past week \_\_\_\_\_minutes
  
5. Yesterday did you listen to music for fun? Yes    No
  - For how long? \_\_\_\_\_minutes
  - If that typical for you? Yes    No
- If no, do you usually listen to music **more** or **less**?
  - Please estimate the amount of time over the past week you spent listening to music for fun \_\_\_\_\_minutes

During the past week, please approximate the amount of time you spent in the following activities:

- |   |               |
|---|---------------|
| 6. Baking (for recreation)                              | _____ minutes |
| 7. Crafts (i.e., sewing, scrapbooks)                    | _____ minutes |
| 8. Gardening (for recreation)                           | _____ minutes |
| 9. Having people over (i.e., party, BBQ)                | _____ minutes |
| 10. Shopping for non-essential items                    | _____ minutes |
| 11. Going to a party                                    | _____ minutes |
| 12. Going to a restaurant                               | _____ minutes |
| 13. Going to the movies                                 | _____ minutes |
| 14. Attending a concert/play/show                       | _____ minutes |
| 15. Going to a sporting event                           | _____ minutes |
| 16. Outdoor recreation (i.e., hunting, fishing, hiking) | _____ minutes |
| 17. Personal exercise                                   | _____ minutes |
| 18. Going to the park or on a picnic                    | _____ minutes |
| 19. Going out to lunch with friends or relatives        | _____ minutes |
| 20. Visiting friends or relatives                       | _____ minutes |
| 21. Attending church/religious services                 | _____ minutes |
| 22. Attending hobby/club/church meetings                | _____ minutes |
| 23. Doing volunteer work in community                   | _____ minutes |
| 24. Swimming for fun, not exercise                      | _____ minutes |
| 25. Going to an amusement park                          | _____ minutes |

## REFERENCES

- Aneshensel, C.S., Frerichs, R.R., Clark, V.A., & Yokopenic, P.A. (1982). Telephone versus in-person surveys of community health status. American Journal of Public Health, 72(9), 1017-1021.
- Barakat, L.P., Kazak, A.E., Meadows, A.T., Casey, R., Meeske, K., & Stuber, M.L. (1997). Families surviving childhood cancer: A comparison of posttraumatic stress symptoms with families of healthy children. Journal of Pediatric Psychology, 22(6), 843-859.
- Barakat, L.P., Kazak, A.E., Meeske, K., Gallagher, P., Cnaan, A., & Stuber, M.L. (1998). Assessing posttraumatic stress in survivors of childhood cancer and their mothers: Development and validation of the impact of traumatic stressors interview schedule (ITSIS) for pediatric oncology. Poster Presentation, Kansas Conference in Clinical Child Psychology.
- Baron, R.M., & Kenny, D.A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. Journal of Personality and Social Psychology, 51(6), 1173-1182.
- Bauman, L.J. (1993). Collecting data by telephone interviewing. Developmental and Behavioral Pediatrics, 14(4), 256-257.
- Biggs, K.S., Heinrich, J., Jekel, J.F., & Cuono, C.B. (1997). The burn camp experience: Variables that influence the enhancement of self-esteem. Journal of Burn Care and Rehabilitation, 18(1), 93-98.
- Bluebond-Langner, M., Perkel, D., Goertzel, T., Nelson, K., & McGeary, J. (1990). Children's knowledge of cancer and its treatment: Impact of an oncology camp experience. Journal of Pediatrics, 116(2), 207-213.
- Botuck, S., & Winsberg, B. (1991). Effects of respite on mothers of school-age and adult children with severe disabilities. Mental Retardation, 29(1), 43-47.
- Breslau, N., Staruch, K.S., & Mortimer, E.A. (1982). Psychological distress in mothers of disabled children. American Journal of Disabled Children, 136, 682-686.
- Briery, B.G., & Rabian, B. (1999). Psychosocial changes associated with participation in a pediatric summer camp. Journal of Pediatric Psychology, 24(2), 183-190.

- Cohen, J. (1992). A power primer. Psychological Bulletin, 112(1), 155-159.
- Crandell, D.L., & Dohrenwend, B.P. (1967). Some relations among psychiatric symptoms, organic illness, and social class. American Journal of Psychiatry, 123(12), 1527-1538.
- Creer, T.L., & Bender, B.G. (1995). Pediatric asthma. In M. C. Roberts (Ed.), Handbook of Pediatric Psychology. (pp. 219-240). New York: Guilford Press.
- Dahlquist, L.M., Czyzewski, D.I., Copeland, K.G., & Jones, C.L. (1993). Parents of children newly diagnosed with cancer: Anxiety, coping, and marital distress. Journal of Pediatric Psychology, 18 (3), 365-376.
- Drotar, D. (1992). Integrating theory and practice in psychological interventions with families of children with chronic illness. In T. J. Akamatsu, M. A. Stephens, S. E. Hobfall, & J. H. Crowthers (Eds.), Family Health Psychology. (pp. 175-192). Washington, DC: Hemisphere.
- DuPaul, G.J., & Kyle, K.E. (1995). Pediatric pharmacology and psychopharmacology. In M. C. Roberts (Ed.), Handbook of pediatric psychology. (pp. 741-758). New York: Guilford Press.
- Fenig, S., Levav, I., Kohn, R., & Yelin, N. (1993). Telephone vs face-to-face interviewing in a community psychiatric survey. American Journal of Public Health, 83(6), 896-898.
- Fielding, D., Moore, B., Dewey, M., Ashley, P., McKendrick, T., & Pinkerton, P. (1985). Children with end-stage renal failure: Psychological effects on patients, siblings, and parents. Journal of Psychosomatic Research, 29(5), 457-465.
- Fournier, L., & Kovess, V. (1993). A comparison of mail and telephone interview strategies for mental health surveys. The Canadian Journal of Psychiatry, 38(8), 525-533.
- George, L.K., & Gwyther, L.P. (1986). Caregiving well-being: A multidimensional examination of family caregivers of demented adults. The Gerontologist, 26(3), 253-259.
- Goldberg, S., Morris, P., Simmons, R.J., Fowler, R.S., & Levison, H. (1990). Chronic illness in infancy and parenting stress: A comparison of three groups of parents. Journal of Pediatric Psychology, 15(3), 347-358.
- Gordon, R.M., Daniele, R.J., & Diller, L. (1992). Stress, appraisal, and coping in mothers of disabled and nondisabled children. Journal of Pediatric Psychology, 17(5), 587-605.

Gortmaker, S., & Sappenfield, W. (1984). Chronic disorders: Prevalence and impact. Pediatric Clinics of North America, 31(1), 3-18.

Grey, M., Lipman, T., Cameron, M.E., & Thurber, F.W. (1997). Coping behaviors at diagnosis and in adjustment one year later in children with diabetes. Nursing Research, 46(6), 312-317.

Hair, J.F., Anderson, R.E., Tatham, R.L., & Black, W.C. (1998). Multiple Analysis of Variance. In J.F. Hair, R.E. Anderson, R.L. Tatham, & W.C. Black, Multivariate Data Analysis. (pp. 326-386). Upper Saddle River, NJ: Prentice Hall.

Halpern, P.L. (1985). Respite care and family functioning in families with retarded children. Health and Social Work, 10(2), 138-151.

Harkavy, J., Johnson, S.B., Silverstein, J.H., Spillar, R., McCallum, M., & Rosenbloom, A.L. (1983). Who learns what at diabetes summer camp. Journal of Pediatric Psychology, 8(2), 143-153.

Hauenstein, E.J. (1990). The experience of distress in parents of chronically ill children: Potential or likely outcome? Journal of Clinical Child Psychology, 19(4), 356-364.

Herman, S., & Marcenko, M.O. (1997). Perceptions of services and resources as mediators of depression among parents of children with developmental disabilities. Mental Retardation, 35(6), 458-467.

Hinkle, A.L., & King, G.D. (1978). A comparison of three survey methods to obtain data for community mental health program planning. American Journal of Community Psychology, 6(4), 389-397.

Hodges, K., Kline, J.J., Barbero, G., & Flanery, R. (1985). Depressive symptoms in children with recurrent abdominal pain and in their families. Journal of Pediatrics, 107(4), 622-626.

Holmbeck, G.N. (1997). Toward terminological, conceptual, and statistical clarity in the study of mediators and moderators: Examples from the child-clinical and pediatric psychology literatures. Journal of Consulting and Clinical Psychology, 65(4), 599-610.

Holroyd, J. (1987). The Questionnaire on Resources and Stress: An instrument to measure family response to a handicapped family member. Journal of Community Psychology, 2, 92-94.

Ireys, H.T., Sills, E.M., Kolodner, K.B., & Walsh, B.B. (1996). A social support intervention for parents of children with juvenile rheumatoid arthritis: Results of a randomized trial. Journal of Pediatric Psychology, 21(5), 633-642.

Jacobson, A.M., Hauser, S.T., Lavori, P., Wolfsdorf, J.I., Herskowitz, R.D., Milley, J.E., Bliss, R., Gelfand, E., Wertlieb, D., & Stein, J. (1990). Adherence among children and adolescents with insulin-dependent diabetes mellitus over a four-year longitudinal follow-up: I. The influence of patient coping and adjustment. Journal of Pediatric Psychology, 15(4), 511-526.

Johnson, S.B. (1995). Managing insulin-dependent diabetes mellitus in adolescence: A developmental perspective. In J. L. Wallander & L. J. Siegel (Eds.), Adolescent health problems: behavioral perspectives. (pp. 265-288). New York: Guilford Press.

Joyce, K., Singer, M., & Isralowitz, R. (1983). Impact of respite care on parents' perceptions of quality of life. Mental Retardation, 21, 153-156.

Kazak, A.E., Segal-Andrews, A.M., & Johnson, K. (1995). Pediatric psychology research and practice: A family/systems approach. In M. C. Roberts (Ed.), Handbook of pediatric psychology. (pp. 84-104). New York: Guilford Press.

Kovacs, M., Finkelstein, R., Feinberg, R., Crouse-Novak, M., Paulauskas, S., & Pollock, M. (1985). Initial psychological responses of parents to the diagnosis of insulin-dependent diabetes mellitus in their children. Diabetes Care, 8, 568-575.

Kovacs, M., Iyengar, S., Goldston, D., Stewart, J., Obrosky, D.S., & Marsh, J. (1990). Psychological functioning of children with insulin-dependent diabetes mellitus: A longitudinal study. Journal of Pediatric Psychology, 15(5), 619-632.

Mack, S.A., & Berman, L.C. (1988). A group for parents of children with fatal genetic illnesses. American Journal of Orthopsychiatry, 58(3), 397-404.

Manne, S.L., Lesanics, D., Meyers, P., Wollner, N., Steiner, P., & Redd, W. (1995). Predictors of depressive symptomatology among parents of newly diagnosed children with cancer. Journal of Pediatric Psychology, 20(4), 491-510.

Marc, D.L., & MacDonald, L. (1988). Respite care--Who uses it? Mental Retardation, 26(2), 93-96.

Matloff, E.T., & Zimmerman, S.J. (1996). Framework for a proactive parent support group: The Syracuse cystic fibrosis model. Journal of Pediatric Health Care, 10, 264-271.

McCormick, M.C., Workman-Daniels, K., Brooks-Gunn, J., & Peckham, G.J. (1993). When you're only a phone call away: A comparison of the information in telephone and face-to-face interviews. Developmental and Behavioral Pediatrics, 14(4), 250-255.



McKinney, B., & Peterson, R.A. (1987). Predictors of stress in parents of developmentally disabled children. Journal of Pediatric Psychology, 12(1), 133-150.

Moffatt, M.E.K., & Pless, I.B. (1983). Locus of control in juvenile diabetic campers: Changes during camp, and relationship to camp staff assessments. Journal of Pediatrics, 103(1), 146-150.

Mullins, L.L., Olson, R.A., Reyes, S., Bernardy, N., Huszti, H.C., & Volk, R.J. (1991). Risk and resistance factors in the adaptation of mothers of children with cystic fibrosis. Journal of Pediatric Psychology, 16(6), 701-715.

Newacheck, P.W., Budetti, P.P., & Halfon, N. (1986). Trends in activity-limiting chronic conditions among children. American Journal of Public Health, 76, 178-184.

O'Toole, B.I., Battistutta, D., Long, A., & Crouch, K. (1986). A comparison of costs and data quality of three health survey methods: Mail, telephone, and personal home interview. American Journal of Epidemiology, 124(2), 317-328.

Patterson, J.M., Leonard, B.J., & Titus, J.C. (1992). Home care for medically fragile children: Impact on family health and well-being. Developmental and Behavioral Pediatrics, 13(4), 248-255.

Pearlin, L.I. (1994). Conceptual strategies for the study of caregiver stress. In E. Light, G. Niederehe, & B. D. Lebowitz (Eds.), Stress effects on family caregivers of Alzheimer's patients: Research and interventions. (pp. 3-21). New York: Springer Publishing Company.

Pearlin, L.I., Mullan, J.T., Semple, S.J., & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 30(5), 583-594.

Phipps, S., Fairclough, D., & Mulhern, R.K. (1995). Avoidant coping in children with cancer. Journal of Pediatric Psychology, 20(2), 217-232.

Pless, I.B., & Pinkerton, P. (1975). Chronic childhood disorder: Promoting patterns of adjustment. London: Henry Kimpton Publishers.

Quittner, A.L., & DiGirolamo, A.M. (1998). Family adaptation to childhood disability and illness. In R. T. Ammerman & J. V. Campo (Eds.), Handbook of pediatric psychology and psychiatry, volume II. (pp. 70-102). Boston: Allyn & Bacon.

Quittner, A.L., DiGirolamo, A.M., Michel, M., & Eigen, H. (1992). Parental response to cystic fibrosis: A contextual analysis of the diagnosis phase. Journal of Pediatric Psychology, 17(6), 683-704.



Quittner, A.L., Gluekauf, R.L., & Jackson, D.N. (1990). Chronic parenting stress: Moderating versus mediating effects of social support. Journal of Personality and Social Psychology, 59(6), 1266-1278.

Quittner, A.L., Opipari, L.C., Regoli, M.J., Jacobsen, J., & Eigen, H. (1992). The impact of caregiving and role strain on family life: Comparisons between mothers of children with cystic fibrosis and matched controls. Rehabilitation Psychology, 37(4), 275-290.

Rimmerman, A. (1989). Provision of respite care for children with developmental disabilities: Changes in maternal coping and stress over time. Mental Retardation, 27(2), 99-103.

Roman, L.A., Lindsay, J.K., Boger, R.P., DeWys, M., Beaumont, E.J., Jones, A.S., & Haas, B. (1995). Parent-to-parent support initiated in the neonatal intensive care unit. Research in Nursing and Health, 18, 385-394.

Rubin, B.K., & Geiger, D.W. (1991). Pulmonary function, nutrition, and self-concept in cystic fibrosis summer campers. Chest, 100(3), 649-654.

Smith, K.E., Gotlieb, S., Gurwitsch, R.H., & Blotcky, A.D. (1987). Impact of a summer camp experience on daily activity and family interactions among children with cancer. Journal of Pediatric Psychology, 12(4), 533-542.

Speltz, M.L., Arnsden, G.C., & Clarren, S.S. (1990). Effects of craniofacial birth defects on maternal functioning postinfancy. Journal of Pediatric Psychology, 15(2), 177-196.

Spevack, M., Johnson, S.B., Riley, W., & Silverstein, J.H. (1989). The effect of diabetes summer camp on adherence behaviors and glycemic control. In J. H. Johnson & S. B. Johnson (Eds.), Advances in Child Health Psychology. (pp. 285-292). Gainesville, FL: University of Florida Press.

Thompson, R.J., & Gustafson, K.E. (1996a). Models of adaptation. In R. J. Thompson & K. E. Gustafson (Eds.), Adaptation to chronic childhood illness. (pp. 131-156). Washington, D.C.: American Psychological Association.

Thompson, R.J., & Gustafson, K.E. (1996b). Psychological adjustment of parents and siblings. In R. J. Thompson & K. E. Gustafson (Eds.), Adaptation to chronic childhood illness. (pp. 157-176). Washington, D.C.: American Psychological Association.

Thompson, R.J., Gustafson, K.E., Hamlett, K.W., & Spock, A. (1992). Stress, coping, and family functioning in the psychological adjustment of mothers of children and adolescents with cystic fibrosis. Journal of Pediatric Psychology, 17(5), 573-585.

Walker, L.S., Ortiz-Valdes, J.A., & Newbrough, J.R. (1989). The role of maternal employment and depression in the psychological adjustment of chronically ill, mentally retarded, and well children. Journal of Pediatric Psychology, 14(3), 357-370.

Wallander, J.L., & Thompson, R.J. (1995). Psychosocial adjustment of children with chronic physical conditions. In M. C. Roberts (Ed.), Handbook of Pediatric Psychology. (pp. 124-141). New York: Guilford Press.

Wallander, J.L., & Varni, J.W. (1998). Effects of pediatric chronic physical disorders on child and family adjustment. Journal of Child Psychology and Psychiatry, 39(1), 29-46.

Wallander, J.L., Varni, J.W., Babani, L., DeHaan, C.B., Wilcox, K.T., & Banis, H.T. (1989). The social environment and the adaptation of mothers of physically handicapped children. Journal of Pediatric Psychology, 14(3), 371-387.

Weeks, M.F., Kulka, R.A., Lessler, J.T., & Whitmore, R.W. (1983). Personal versus telephone surveys for collecting household health data at the local level. American Journal of Public Health, 73(12), 1389-1394.

Weinfurt, K.P. (1995). Multivariate analysis of variance. In L. G. Grimm & P. R. Yarnold (Eds.), Reading and understanding multivariate statistics. (pp. 245-276). Washington, D.C.: American Psychological Association.

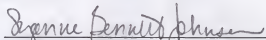
Wells, K.B., Burnam, A., Leake, B., & Robins, L.N. (1988). Agreement between face-to-face and telephone-administered versions of the depression section of the NIMH Diagnostic Interview Schedule. Journal of Psychiatric Research, 22(3), 207-220.

Wysocki, T., Huxtable, K., Linscheid, T.R., & Wayne, W. (1989). Adjustment to diabetes mellitus in preschoolers and their mothers. Diabetes Care, 12(8), 524-529.

### BIOGRAPHICAL SKETCH

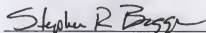
Lisa Joan Meltzer earned her Bachelor of Arts in psychology from Pomona College, Claremont, CA. She earned her Master of Science in clinical and health psychology from the University of Florida, Gainesville, FL. After a clinical internship at the Children's Hospital of Philadelphia (PA) she anticipates earning her Doctor of Philosophy in clinical and health psychology from the University of Florida, Gainesville, FL., in August, 2002.

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



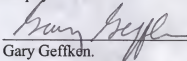
Suzanne Bennett Johnson, Chair  
Professor of Clinical and Health  
Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



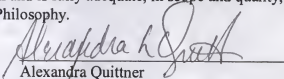
Stephen R. Boggs  
Associate Professor of Clinical and  
Health Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



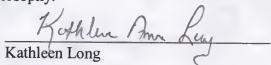
Gary Geffken.  
Affiliate Associate Professor of Clinical  
and Health Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



Alexandra Quittner  
Professor of Clinical and Health  
Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



Kathleen Long  
Professor of Nursing

This dissertation was submitted to the Graduate Faculty of the College of Health Professions and to the Graduate School and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

August 2002

  
Dean, College of Health Professions

---

Dean, Graduate School

